National Head and Neck Cancer Audit

The Information Centre
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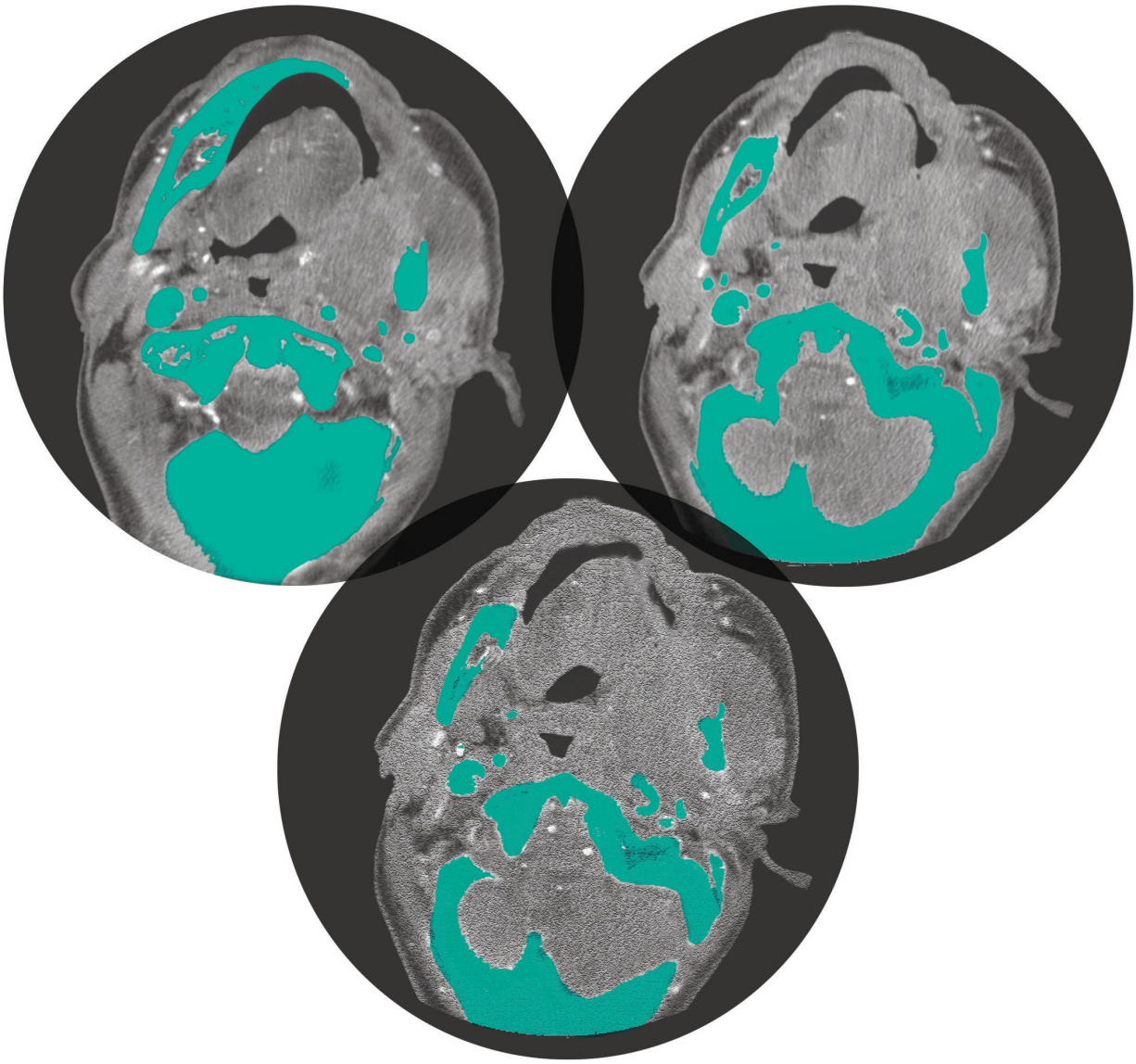
Key findings for England and Wales for the audit period October 2005 to November 2006

DAHNO Second Annual Report



Prepared in association with:

Healthcare Commission

British Association of Head and Neck Oncologists

FOR HEALTH AND SOCIAL CARE

NHS

"The audit has continued to explore and consolidate a wide range of information on head and neck cancers. The data quality presented will benefit not only healthcare providers by showing the gaps in provision; it will help to provide a better service for the head and neck cancer patients. The DAHNO team are to be congratulated for their commitment and hard work. There is much more to be done!"

Christine Piff, Founder and Chief Executive, Lets Face it

"Like any new procedure, there is a learning curve that can be overcome within a few months and the process becomes embedded in routine practice. The long-term benefits of prospective high quality data collection simply outweigh the initial problems involved in setting up the process."

Vinidh Paleri, Consultant Surgeon, Department of ENT - Head and Neck Surgery, Newcastle-upon-Tyne Hospital NHS Trust

"It is true to say that, as yet, not every Head and Neck Surgeon or Oncologist in the UK has comprehensively embraced the concept of DAHNO. However, whilst individual clinicians may have doubts about its role, the Department of Health does not. It is increasingly evident that this data will be used as an indicator of clinical performance and as an instrument to guide resource allocation. Therefore, it is imperative that we, as a body, overcome any personal prejudice to ensure that DAHNO works for us and is a true reflection of the clinical activity and outcomes currently being undertaken and achieved in the UK".

Terry Jones, Senior Lecturer in Head and Neck Surgery/ Otolaryngology, University of Liverpool, Honorary Consultant Otolaryngologist/Head and Neck Surgeon, University Hospital Aintree, Liverpool, UK

"Uncommon tumours require comprehensive national data collection to allow meaningful audit. It would be encouraging if doctors who profess an interest in head and neck oncology, from units yet to contribute, could submit data to DAHNO. Optimising this audit will benefit both patients and clinicians".

Jonathan Hayter, Consultant Maxillofacial Surgeon, Leicester Royal Infirmary

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National head and neck cancer audit key findings for England and Wales for the audit period October 2005 to November 2006

This second report for the national head and neck cancer audit presents data collected on new registrations from 1 October 2005 to 31 October 2006 and treatment data up to the 23 November 2006. The report reflects findings from the analysis of that data, and provides recommendations for improving data quality and completeness. The national head and neck cancer audit aims to improve both the volume and quality of data submissions, and from this, provide comparative feedback to NHS Provider Trusts, with the ultimate aim of improving patient care.

Electronic copies of this report can be found at: www.ic.nhs.uk (or for DAHNO users www.DAHNO.com) Printed copies of this report can be ordered from The Information Centre for health and social care's Contact Centre 0845 300 6016 or email: enquiries@ic.nhs.uk quoting document reference 18010702. For further information about this report, email: enquiries@ic.nhs.uk.

A brief summary report will compliment this report following its publication. In addition, Provider Trusts meeting certain criteria will be issued with a local report in July 2007, comparing selected indicators against the national average.

For further information about this report, email: enquiries@ic.nhs.uk or contact:

National Clinical Audit Support Programme (NCASP)
The Information Centre for health and social care
1 Trevelyan Square
Boar Lane
Leeds
LS1 6AE

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I. Acknowledgements

The National Head and Neck Cancer Audit was commissioned and sponsored by the Healthcare Commission and developed in partnership with the British Association of Head and Neck Oncologists (BAHNO).

The project wishes to acknowledge the following individuals and groups who have supported the audit project and provided guidance during the data collection period October 2005 to November 2006 and during the compilation of this report.

Dick Waite and Helen Laing of the Healthcare Commission, for their continued sponsorship and support for the audit.

The DAHNO project team: Chair, Richard Wight; Vice Chair, Graham Putnam; Project Manager, Paul Theato; Senior Project Manager (Cancer Audits), Steve Dean; DAHNO Application Developer, Ronnie Brar; NCASP Programme Support Officer, Caroline McGregor- Johnson; Project Support Officer, Mary Boden; Previous Project Support Officer, Kerry Agar.

Nick Worner, Lizzie Whewell and Charlotte Tye of The Information Centre for health and social care (The IC) Marketing and Communications Team for their assistance throughout the year in publicising the audit, assisting with the planning of workshops and with the publication of this report. Isis Hreczuk-Hirst of The IC Datasets team for her support of data-related issues.

Jeff Stamatakis, Wayne Yellen, Jackie Davies at Informing Healthcare for their support in bringing Wales into the audit during 2006.

The following groups have supported the audit, including; the Data Management and Analysis Group; the User Group; the Head and Neck Clinical Reference Group, (full list of members and contributing professional organisations in Appendix 2 and 3).

We would like to acknowledge the Expert Panels (larynx and oral cavity) who contributed greatly to the annual report; Patrick Bradley, Terry Jones, Mark Watson, David Howard, Jon Hayter, Cyrus Kerawala, Iain McVicar, Chris Nutting.

NHS Connecting for Health and previously the NHS Information Authority supported the technical infrastructure. We would particularly like to acknowledge Gary Sargent and Sandy Garrity who provide helpdesk support to users.

We would also like to acknowledge David Cunningham for the initial development of the DAHNO application and Ronnie Brar for continued development and system maintenance.

The analysis for this report was undertaken by the cancer registries and special thanks must be given to Andy Pring from the South West Public Health Observatory, Sandra Edwards from the Oxford Cancer Intelligence Unit and, with the support of Ruth Jack and Henrik Møller at the Thames Cancer Registry.

Finally, thanks go to all those organisations that have participated in the audit so far, and for the individual contributions of clinicians, managers and administrative staff without whose efforts the audit would not be able to deliver.

Thank you also to all those patients whose data is contributing towards bringing about improvements in the provision of care and outcomes for all those similarly afflicted by head and neck cancer.

II. Foreword

National clinical audits have the potential to synthesise information on the quality of care delivered to all patients with a particular condition across the country. Experience in other areas of healthcare has shown that feedback of comparative information to hospitals and teams involved in the delivery of care can and does lead to improvements in service quality. Furthermore, such information will in the future inform stronger commissioning and will empower patients to make informed choices about their care.

I commend the hard work done by everyone who has contributed to this second report on the DAHNO audit. This includes the DAHNO project team, the expert panels, cancer registries and representatives of the Healthcare Commission and the Information Centre as well as clinicians and managers in many head and neck cancer teams. In total, this audit relates to over 1,400 patients with cancer of the larynx or oral cavity. Importantly several cancer networks should be commended for providing data on all or almost all of the incident cases in their population.

There are, however, no grounds for complacency. In England, only around 47 per cent of incident cases are being reported to the DAHNO audit. It is impossible to know whether this is a representative sample. I am equally concerned that amongst reported cases only 54 per cent had information on T (tumour) and N (nodal) staging and only 40 per cent had information on performance status. This is despite the fact that 80 per cent were reported to have had a care plan and over 7 per cent were reported to have been discussed at a multi-disciplinary team (MDT) meeting. Such meetings provide an ideal opportunity to confirm details on staging, performance status and comorbidity.

Success of the DAHNO audit depends on the contribution of participants and better coverage across cancer networks. Hospitals and head and neck teams must improve the supply of information to the audit in future years. We owe it to our patients to do so. Casemix adjusted data on outcomes for patients undergoing cardiac surgery is now routinely published in this country. This is one of the areas we are carefully considering as part of the development of the Cancer Reform Strategy.

Prof Mike Richards
National Cancer Director

This is the first year that head and neck cancer clinical teams from the three cancer networks in Wales have participated in the DAHNO audit. This has involved a concerted effort and I must acknowledge the work of everyone involved, in particular, Simon Hodder, Chair of the All Wales Head and Neck Cancer Steering Group. I must also thank Jeff Stamatakis who Chairs the Cancer Information Framework Group and leads the Cancer Network Information System Cymru (CaNISC) team.

It is encouraging that in our first year of participation in the audit we have a case ascertainment from Wales of 83 per cent. Following on from the main DAHNO report we will be producing a supplementary document focussing on the Welsh data with associated recommendations.

Jane Hanson

Dr Jane Hanson
Advisor for Cancer Services to the Wales Assembly Government and Director of the Cancer Services Co-ordinating Group

Another year and further significant strides have been made delivering comparative audit in head and neck cancer. This success is dependent on contributions made by individual clinicians and their support staff across the country. This annual report represents their continuing labours, facilitated and supported by NHS Provider Trusts and Cancer Networks.

Peer commitment has acted as a spur for others to join, and the aim remains to achieve comprehensive and consistent coverage to produce meaningful results, that will inevitably improve the outcome of patients with head and neck cancer.

This audit has significantly benefited from the knowledge and commitment of the National Clinical Audit Support Programme (NCASP) team, and the continued support of the Healthcare Commission.

The second annual report, examines data submitted from October 2005 until November 2006. Organisations have joined at different points since the inception of the audit in 2004. The audit is delighted to have been joined for the first time by colleagues in Wales.

This report describes the methods, results and themes arising so far. Further pieces of the jigsaw have been added and as completeness and comprehensiveness of submissions increase a full picture of head and neck cancer care will emerge. This is another major step along this road.

Richard Wight FRCS
Consultant Head and Neck Surgeon
DAHNO Project Chair

Graham Putnam FRCS
Consultant Head and Neck Surgeon
DAHNO Project Vice Chair

1.0 Executive Summary

The DAHNO second annual report on the management of head and neck cancer in England and Wales includes a background to head and neck cancer (Section 2) and a description of the infrastructure, methods and analysis used within the audit (Sections 3 to 7). Detailed findings in Section 8 cover outcomes in both carcinoma of the larynx and oral cavity. Detailed recommendations and conclusions are in Sections 9 and 11.

Throughout the document significant points for consideration are shown in shaded green boxes, whilst practical examples of methods that improve data collection and collation can be found in Appendix 10 and at: www.ic.nhs.uk (or for DAHNO users www.DAHNO.com).

Submission by Provider Trust/Cancer Network is found in Section 8.3 and Appendix 1.

1.1 What is DAHNO?

DAHNO (**D**ata for **H**ead and **N**eck **O**ncology), provides a continuous electronic comparative audit on the management of head and neck cancer. It is supported by professional bodies and sponsored by the Healthcare Commission. The audit will allow national assessment of outcomes and provide a tool to improve standards of care, identifying areas of good practice to teams delivering head and neck cancer care.

The disease burden of head and neck cancer is significant. Patients require intensive investigation, multi-modality treatments and rehabilitation with long-term support to achieve an adequate recovery. Given the significant resource requirements of patients with head and neck cancer, there is an absolute need to collect data to more accurately reflect the healthcare burden imposed by head and neck cancer, to gain commissioner support leading to improved outcomes for patients.

Core issues addressed in the first phase of the DAHNO Project are:

- delivery of appropriate primary treatment (including adjuvant therapy) in the management of head and neck cancer affecting the larynx and oral cavity by a multi-professional team
- delivery of care to agreed standards.

1.2 What DAHNO adds to existing information

Cancer waiting times provide information on timeliness of treatment. However, current information and monitoring arrangements do not provide direct information on the appropriateness of treatment. To determine this, anonymised data on individual patients needs to be collected and analysed. The head and neck cancer audit, continuously collects data at each patient service contact, and this record is continually updated. Clinical aspects of staging and other casemix factors can be more easily collected. Collecting data for the head and neck cancer audit will enable easier and better quality data capture for cancer registries.

1.3 Where head and neck cancer care happens - submission rates

1.3.1 Contributing Cancer Networks

The second annual report covers the period 1 October 2005 to 31 October 2006 and for the first time includes data from Wales. Each of the thirty-three Cancer Networks in England and the three in Wales have had an opportunity to contribute.

Twenty-six English Cancer Networks and all three Welsh Cancer Networks have submitted patient records, and the second annual report describes results for over 1,400 patient records. Nine Cancer Networks have managed to achieve high levels of registration with approaching 100 per cent of the expected case numbers recorded.

1.3.2 Overview of case ascertainment

The data collection period (13 months) showed a rise in case ascertainment to 49 per cent (1,443 of an estimated 2,945 cases in England and Wales) with data completeness varying for each patient record. In England, 1,283 cases of an estimated 2,753 cases were submitted (47 per cent) which is a significant rise with varying data completeness.

In Wales, 160 cases of an estimated 192 cases were submitted (83 per cent), which is a high level but again with varying data completeness.

Whilst the improved case ascertainment is welcomed, ***executive teams in organisations yet to contribute should ensure priortisations of DAHNO in their audit programmes***. Participation in the Head and Neck (DAHNO) audit is part of the Healthcare Commission's Annual health check, and the peer review process commencing in 2007/2008.

Complete and comprehensive submission provides a vehicle for assurance to trust boards and patient groups of the quality of care delivered in head and neck cancer. Additionally with complete data submission it will become possible to identify areas where action is required to ensure that care is improved to the highest standards.

1.4 Key overall findings

1.4.1 The pivotal role of the multi-disciplinary team (MDT) meeting

Patient expectations and Improving Outcomes Guidance (IOG) measures are that all care discussions are held, and decisions made, at an MDT meeting. Head and neck cancer teams need to provide assurance to trust boards on this aspect of care delivery.

71.6 per cent of patients are confirmed as having been discussed at a MDT meeting. A small number (0.8 per cent) were recorded as not having been discussed, but 24.6 per cent did not have this important item recorded. This leaves doubt still, that treatment decisions for patients could be being made outside of MDTs.

Staging, comorbidity and performance status are key influences on outcome. The Expert Panels are unanimous that all ***MDTs must ensure the recording of staging information on 100 per cent of patients***. Recording cancer site and accurate stage is a medical responsibility with best practice suggesting that this should be clearly documented at the MDT. To allow future analysis to accurately risk adjust, and allow a true comparison between organisations, MDTs should record these factors routinely.

1.4.2 Speech and language and dietetic provision

Pre-treatment speech, swallowing and dietetic assessment is recorded for only a small percentage of registrations and is likely to reflect poor data quality. Whilst the expert panel members believe that this is not a true reflection of current practice, they are aware of nationwide shortages in allied health professional roles to support cancer MDTs. Patient representatives feel it is imperative that speech and swallowing and dietetic support is available to all patients with head and neck cancer from the point of diagnosis. The provision of appropriate professional support should be seen as a priority requirement.

The Expert Panel members realise this has significant resource implications, but their view is also that speech and language therapists (SALT) and dietetic input is mandatory. They hope all MDTs strive to achieve this input. Resource bids would be supported by accurate data collection, helping to quantify deficit, and its correct capture onto the DAHNO application would identify the national profile of provision.

1.5 Who receives the care?

745 cases of larynx cancer and 698 cases of oral cavity cancer were submitted.

Cancer of the larynx and oral cavity, is again shown as a disease of older age groups in the pooled data of 34 months of data collection (90 per cent greater than 50 years old) with males predominating.

1.5.1 The patient journey

A smaller number of patients show delays in diagnostic imaging, which is an improvement from the first report. ***Local teams should assess the timeliness of imaging and seek to reduce delay if applicable***.

The investigation of cancer wait times was expected to reduce patient journey times, whilst the median time has reduced in the study period, considerable work remains to achieve these targets for all patients. Booked care and clearly defined patient pathways are key factors to minimise delay. The site specific group should see performance reporting as a routine agenda item at all its meetings, supported by monitored action plans if avoidable delay is evident.

1.5.2 Care provided

In the treatment of laryngeal cancer patients, radiotherapy remains the most common first treatment. However a possible trend is noted with an increase in treatment via endolaryngeal resection. The current evidence base does not support the superiority of one treatment over another. DAHNO provides a unique opportunity to track this and other treatment changes in a high quality clinical database containing sufficient information to allow casemix adjusted outcomes. For surgery, the median interval from diagnosis to first recorded treatment is 24 days but for those undergoing primary radiotherapy a

median time of 45 days was found. A small reduction when compared to the first report.

The majority of oral cavity patients have surgery as a first treatment with a median time to operation of 34 days from diagnosis. For the smaller number who undergo primary radiotherapy the median interval to commencement of treatment is 48 days.

Whilst the interval to commencing radiotherapy has reduced, as highlighted in last years report, this still suggests that head and neck cancer patients continue to have difficulty in accessing radiotherapy services. Provider organisations for radiotherapy should review patient pathways, as well as the resource committed to head and neck cancer, with the aim of avoiding unnecessary delays.

The Expert Panels noted the importance of collection of actual care delivered along the whole patient pathway and that this is currently inadequate, to allow proper assurance in the complex multi professional management of head and neck cancer.

1.6 Recommendations

The second analysis has again demonstrated variability in record completeness between different organisations and between individual records. High levels of submission and completeness of records are required to gain the most value from the audit. NHS Provider Trusts and Cancer Networks should facilitate data collection through the MDT by providing resources, training and direction.

Multi-disciplinary teams (MDTs) and site specific groups should review the recommendations below and develop action plans for any deficiencies.

Multi-disciplinary teams (MDTs) should:

- ensure timeliness of pathways to meet national access targets
- ensure the awareness and involvement of general dental practitioners and community dental services in urgent cancer referral processes
- ensure that tumour staging (TNM) is confirmed and recorded prior to care planning and following surgical procedures
- ensure that good dental health is maintained throughout treatment
- ensure provision of surgical voice restoration counselling, pre treatment, for all patients having a laryngectomy
- ensure provision of swallowing counselling, pre-treatment, for all patients who are about to undergo oral/oropharyngeal resective and reconstructive surgery with free tissue transfer or partial laryngo-pharyngeal surgery
- should ensure that delays in commencement of radiotherapy/chemotherapy, either as primary or adjunctive treatment are minimised.

1.7 Key aspects for the current collection year 1 November 2006 to 31 October 2007

Future versions of this annual report will report outcomes by contributory provider trust and team, thus the importance of routine collection of factors that contribute to risk adjustment to allow true comparisons to be made.

The British Association of Head and Neck Oncologists (BAHNO) council has formed a small group to define current standards for the delivery of head and neck cancer care. If accepted they will form a national set of standards for the delivery of head and neck cancer care, that will facilitate critical appraisal of the care pathway and provide information to support both local and national developments in this complex area of healthcare delivery. The intention of the audit for the next Annual Report is to compare data submissions against agreed standards subject to BAHNO agreeing the standards.

1.8 Summary report

A summary report is in preparation and will be issued in May 2007. Its focus is for a wider audience beyond the professional head and neck community. It will be available on line at: www.ic.nhs.uk (or for DAHNO users www.DAHNO.com).

1.9 Connected and Contributing Cancer Networks and Provider Trusts

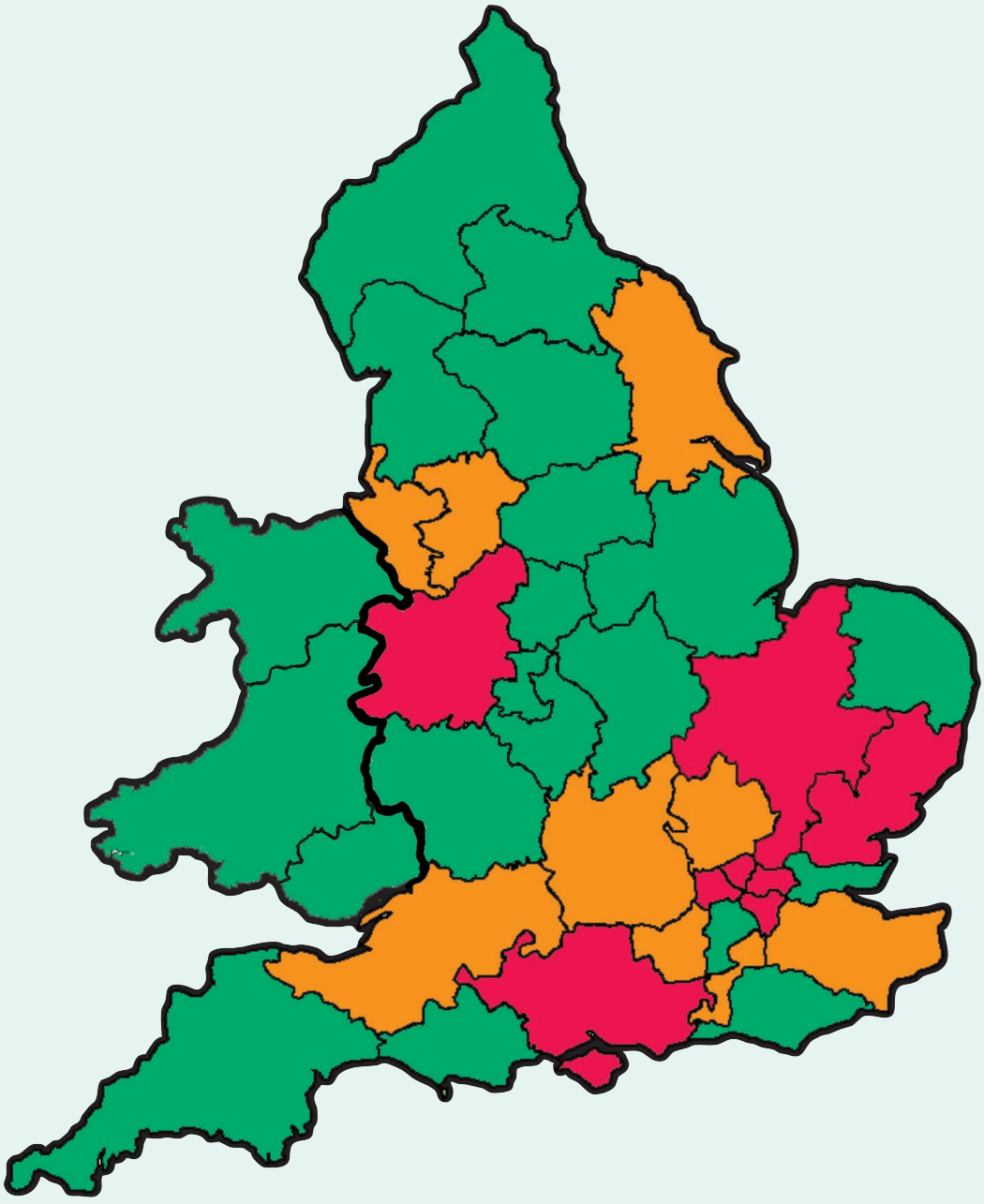
The table and colour coded maps in this Section represent the connectivity and data submission status of Cancer Networks in England. Please note: this table does not take into account whether the data supplied was valid for audit purposes or not (see maps).

Figure 1.5.a: Table of English Cancer Networks showing Provider Trust connectivity status

Cancer Network	Total No. of valid Trusts*	No. of valid Trusts that have uploaded some data to the DAHNO database since 2004	No. of valid Trusts connected but who have never submitted data	No. of valid Trusts that have never connected
Arden	3	2	1	0
Avon Somerset and Wiltshire	6	2	2	2
Central South Coast	5	0	2	3
Derby Burton	2	1	1	0
Dorset	3	3	0	0
Greater Manchester and Cheshire	12	6	4	2
Greater Midlands Cancer Network	4	0	4	0
Humber and Yorkshire Coast	3	1	1	1
Kent and Medway	5	2	1	2
Lancashire and South Cumbria	4	3	1	0
Leicestershire, Northamptonshire and Rutland	3	3	0	0
Merseyside and Cheshire	8	7	1	0
Mid Anglia	3	2	0	1
Mid Trent	4	4	0	0
Mount Vernon	4	1	2	1
Norfolk and Waveney	3	2	0	1
North East London	6	0	4	2
North London	4	2	2	0
North Trent	5	3	0	2
Northern	4	3	1	0
Pan Birmingham	3	3	0	0
Peninsula	5	4	1	0
South East London	3	0	2	1
South Essex	2	1	1	0
South West London	4	3	1	0
Surrey, West Sussex and Hampshire	5	1	1	3
Sussex	3	3	0	0
Teeside, South Durham and North Yorkshire	2	1	1	0
Thames Valley	5	2	0	3
Three Counties	3	2	1	0
West Anglia	6	0	3	3
West London	7	1	0	6
Yorkshire	3	2	1	0
TOTAL	**142**	**70**	**39**	**33**

**Only those Trusts actually submitting or intending to submit data to DAHNO are counted. Trusts that provide head and neck services but submit their data through another Trust are excluded from the count.*

1.9.1 Map showing the contribution status of Cancer Networks in England and Wales reflecting the number of advised Provider Trusts that have submitted valid data (i.e. data for the period 1 October 2005 to 23 November 2006) suitable for inclusion in the second DAHNO annual report.



Cancer Networks where equal or greater than 50 per cent of Provider Trusts have submitted valid data for the second annual report

Cancer Networks where at least one Provider Trust has submitted valid data for the second annual report

Cancer Networks where no Provider Trusts submitted valid data for the second annual report

2.0 Background to head and neck cancer

2.1 What is head and neck cancer?

Head and neck cancer describes a variety of neoplasms in the head and neck region. The definition excludes tumours of the brain and related tissues. Arising principally from the mouth (oral cavity), voice box (larynx) and throat / upper gullet (pharynx), head and neck cancers are amongst a group of the less common cancers, with approximately 6,700 new cases diagnosed in England and Wales each year[1] [2] (ICD Codes C0-C14 and C30-C32).

The most common cancer sites are larynx and oral cavity, and more than 90 per cent of all malignant tumours in the head and neck are squamous cell carcinomas (SCC) arising from the lining mucosa. There is, however, a wide distribution of other cancer sites and histologies providing a broad spectrum of disease.

Metastases from head and neck cancers are present in a significant minority of cases with an orderly spread via the lymphatic system in the neck. Distant metastases occur less commonly. Metastases from other cancers to the head and neck are rare.[3] Patients may present with more than one primary cancer.[4] [5]

The main contributory factors to developing head and neck cancer are tobacco, alcohol and a poor diet, and there is an association with living in areas of deprivation.[6] [7] [8]

Common presenting symptoms include hoarseness, sore throat, difficulty in swallowing, and ulceration or swellings of the oral mucosa and tongue.

The majority of patients present with advanced disease, and provide a substantial and complex challenge to the managing team. Cancer of the head and neck inevitably has a substantial impact on patients.

2.2 Pathway of care

Head and neck cancer may be detected by general medical practitioners, general dental practitioners/ community dental services, or through patient self-referral to hospital. Having entered the secondary care head and neck cancer treatment pathway, the patient can expect an outpatient appointment where an initial examination is performed and further diagnostic procedures ordered if appropriate. These may involve endoscopy, computed tomography, neck ultrasonography,[9] magnetic resonance imaging, fine needle aspiration of any enlarged lymph nodes and surgical biopsy of the lesion. The goal of diagnosis is to detect the presence of a tumour and to stage the cancer according to the International Union Against Cancer's (UICC) classification system.[10]

Head and neck cancer treatment requires a wide range of expertise. In the UK, head and neck cancer treatment is organised around multi-disciplinary teams (MDTs). MDTs[11] may include: surgeons (ENT, maxillofacial, plastic surgery), clinical oncologists, psychologists, dentists, nursing (Macmillan nurses, nurse counsellors), dieticians, speech and language therapists (SALT), physiotherapists, histo-pathologists, cytologists, radiologists, molecular biologists, social workers, epidemiologists, and palliative care physicians. MDTs hold regular meetings where the needs of individual patients are discussed and the appropriate care allocated.

Management of squamous cell carcinomas of the head and neck will depend on cancer site, stage and presence of nodal metastases (generally to the neck). Radiotherapy, surgery and chemotherapy are utilised in head and neck cancer depending on the nature and extent of the disease. The patient can then expect regular follow-up appointments where their clinical status is assessed, with further diagnostic interventions as required. Patients will enter a rehabilitation pathway immediately following the initial treatment phase. In patients with incurable disease, a palliative regimen will be implemented.

2.3 Larynx and oral cavity - burden of disease

2.3.1 Cancer sites

The following anatomical cancer sites are covered by the head and neck cancer audit:

- oral cavity: ICD-10 codes C02-C06 (buccal mucosa, lower and upper alveolus, lower and upper gingiva, hard palate, dorsal and inferior tongue, floor of mouth)

- larynx: ICD-10 codes C10.1, C32.0, C32.1, C32.2, C32.8, C32.9 (supraglottis (including lingual surface of epiglottis), glottis and subglottis).

Of the 233,621 cancers (excluding non-melanoma skin cancers) registered in England in 2004, cancers of the larynx (C32) accounted for 1,693 cases (0.72 per cent) and cancers of the oral cavity (C02-C06) accounted for 1,990 cases (0.85 per cent). These cancer registrations are more likely to be male (84 per cent for cancer of the larynx and 59 per cent for oral cavity).[1]

Of the 16,857 cancers reported by the Welsh Cancer Intelligence Support Unit to the Office for National Statistics in 2004, cancers of the larynx and oral cavity accounted for 186 cases (1.1 per cent). These cancer registrations are more likely to be male (79 per cent for cancer of the larynx and 69 per cent for mouth, lip and oral cavity).[2]

In the first phase of the audit, these two cancer sites were chosen for study because of their higher incidence rates relative to other head and neck cancers, and because they are relatively homogeneous in terms of aetiology and prognosis and have relatively clear anatomical definition. Thus larynx and oral cavity represent approximately 50 per cent[1 2] of all head and neck cancer registrations in England and Wales.

Proposals for the second phase of the audit have just completed a period of consultation and seek to extend the anatomical sites covered. They will be introduced for the collection year commencing November 2007.

2.3.2 Impact of head and neck cancer on patients

The disease burden of head and neck cancer is significant. Patients require intensive investigation, multimodality treatments and prolonged rehabilitation with long-term support to achieve an adequate recovery.

The impact of disease on functions such as eating, drinking, speech, swallowing, smell, breathing and normal social interaction and work capabilities is significant.

Second primaries and locoregional recurrence in either the treated field or upper aerodigestive tract, mean that continued long-term surveillance is desirable.

2.3.3 Outcome in head and neck cancer

Cancers of the larynx and oral cavity are associated with significant mortality, for example, five-year survival for larynx cancer is around 50 per cent. The cancer mortality to incidence ratio is the ratio of patients dying with that cancer in a year to the number new patients registered the same year. For example, if the same number of patients died each year as new cancers were diagnosed, the ratio would be one and if very few patients died, the ratio would approach zero. For all cancers of the larynx (C32), the ratio is 0.37 for males and 0.46 for females. The ratios for cancers of the lip, mouth and pharynx (C00-C14) are 0.44 for males and 0.41 for females.[1] These are comparable to ratios for prostate cancer (0.42) and cervix (0.41) and approach ratios for cancer of the colon (0.53).[12]

Better prognosis is associated with early detection, while late presentation and neck node metastasis drastically reduce long-term survival. The relatively poor survival prognosis for head and neck cancers is linked to lifestyle factors, comorbidity, late presentation and the high median age of incidence.[13]

3.0 Introduction to head and neck comparative audit

3.1 Measuring clinical care

Measuring clinical care has proven to be notoriously difficult. Variations in casemix and resource have confounded attempts to define good and bad practice. Establishing a national baseline is the first step in defining existing care delivery. Improving outcomes guidance has defined a model of care delivery and thirty three local delivery plans (LDPs) have been defined. Measures of compliance against the improving outcomes guidance have been issued and a peer review process will commence in 2007. National audit provides a tool to assess compliance with these defined standards and identify resource limitations. Measuring clinical care is more than ticking boxes to achieve compliance. It should include a local re-appraisal of care delivery methods, and the ability to compare local standards and nationally derived figures is a significant advance.

3.2 Sources of existing information and differences that the head and neck cancer audit provides

Collection of head and neck cancer data in the United Kingdom has evolved from individual committed clinicians' personal recording of patient cases, and cancer registries meeting statutory requirements. The latter, until recently, has lacked stage information, and this has hindered production of outcome and stage adjusted survival data.

Individual institutions case series and reporting of treatments have lacked comprehensive cover and multi-organisational comparison.

At first sight, the data collection method used by the head and neck cancer audit and the cancer registries, appear opposite and exclusive. Cancer registries currently collect selected data on all cancer patients, their tumours and tumour characteristics (pathology, stage), treatment category and outcome. Since cancer management takes place in many locations and the initial treatment episode may take months, most registries make a single data extraction (or collation in the case of electronic registries) several months after diagnosis, in order to avoid repeated access of the clinical record.

The head and neck cancer audit on the other hand, continuously collects data at each patient service contact, and this record is continually updated. Clinical aspects of staging and other casemix factors can be more easily collected.

It is hoped that mechanisms facilitating collecting data for the head and neck cancer audit will enable easier and better quality data capture for cancer registries.

Given the significant resource requirements of patients with head and neck cancer, the first phase of the national audit has focussed on the process and delivery of multi-disciplinary assessment. There is a need to collect data to more accurately reflect the healthcare burden imposed by head and neck cancer.

With time this data will allow national assessment of outcomes and provide a tool to improve standards of care, identifying areas of good practice to the wider group of teams delivering head and neck cancer care.

3.3 Randomised controlled trials (RCT) and meta-analysis in head and neck cancer

The gold standard of evidence in assessing the efficacy of different therapies is a randomised controlled trial or a systematic review of a number of randomised trials with specific statistical methods employed (meta analysis).

In head and neck cancer, the complexity of the disease and its treatment has meant that very few randomised trials exist or are likely to be performed. Meta analyses, such as the application of chemotherapy,[14] have only been published in specific areas.

The head and neck cancer audit will help fill this void of evidence by building a High Quality Clinical Database (HQCD) from consecutive cases. This database will provide both comprehensive and accurate information, including recording patient details that affect outcome. With sufficient data on confounding variables, risk adjusted comparisons can be made. The ensuing large volume of data allows sub-group analysis which in turn allows true comparison of the specific extent of disease and not just of aggregated disease status. HQCDs also facilitate local audit and comparison to peer and are cost effective means of wide-scale clinical engagement.[15]

3.4 Developing comparative audit in head and neck cancer

3.4.1 The DAHNO Project

The detailed history of the DAHNO project has been described in the DAHNO first annual report: *Key findings from the First National Head and Neck Cancer Audit*[16]

In 2002, The British Association of Head and Neck Oncologists (BAHNO) agreed to join forces with partners to deliver a national comparative audit based upon the National Cancer Data Set (NCDS) subset for head and neck cancer. The project, called **DAHNO** (**D**ata for **H**ead and **N**eck **O**ncology) which manages the head and neck cancer audit, has provided both a technical infrastructure for data collection across England as well as facilities for local and central data analysis to deliver continuous comparative audit on the management of head and neck cancer. Data from Wales has been collected within the Cancer Network Information System Cymru (CaNISC)[17] and uploaded for the first time to DAHNO in 2006. The DAHNO project has been and continues to be sponsored by the Healthcare Commission.

3.4.2 Why is comparative audit in head and neck cancer important?

Head and neck cancer professionals, have found the absence of accurate systematic prospective data collection, a major obstacle to improving care standards in the United Kingdom.

There are a number of key areas relating to head and neck cancer, which, if properly addressed, would be likely to have an impact on the incidence and outcomes of the disease. These can be summarised as follows:

i) prevention[18] (e.g. reduction in cigarette smoking and alcohol consumption)

ii) earlier presentation of patients to secondary care (including screening)

iii) timely and appropriate referral from the 'diagnostic' team to 'therapy' team (including process of staging)

iv) management by multi-professional specialist teams

v) consistent standards and patterns of treatment

vi) timely access to treatment.

Multi-professional management is recognised as the gold standard, bringing substantial benefits. There is good evidence however of widely differing standards of care between different parts of the UK and even within the same region, but as yet no comprehensive mapping of care delivered has occurred. Patterns of care delivery vary and a variety of different specialties provide care. The improving outcomes guidance was produced by the National Institute for Clinical Excellence (NICE) in 2005,[19] and it is timely that there is now a national comparative audit to better understand current provision as well as to provide a yardstick to measure the impact of change.

A previous audit by BAHNO has confirmed variation in management across geographically similar areas, and a variation in outcome. Reasons for this are unclear and could relate to a number of different factors:

- differing standards of clinical practice
- differing levels of comorbidity
- differences in stage of disease at presentation
- variations in access to specialist treatment services
- artefacts of analysis methods in calculation of the population 'denominator' when deriving the treatment 'proportions'.

If we could match the outcomes from the districts with the lowest rates to approaching those of the highest, we would probably be able to significantly improve the long-term survival rate in head and neck cancer without any advances in therapy.

Initially, the head and neck cancer audit has focused on adherence to pre-determined process standards. A group led for BAHNO by Professor Martin Birchall is currently developing a review of standards applicable to the audit. In time it is intended that the head and neck cancer audit will have sufficient power to allow examination of the relationship between standards of care and patient outcomes, such as mortality.

Timeliness of treatment, reflects a number of different aspects of care delivery, but is likely to be influenced in part by the resources of the service both in terms of equipment and manpower.

The core issues addressed in the first phase of DAHNO are:

- delivery of appropriate primary treatment (including adjuvant therapy) in management of head and neck cancer affecting the larynx
- oral cavity by a multi-professional team, and
- delivery of care to agreed standards.

3.5 Key partners and drivers in developing clinical audit

3.5.1 The National Clinical Audit Programme (NCASP) and Patient's Outcomes Programme

Both the National Clinical Audit Programme (NCASP) and Patients' Outcomes Programme, (Healthcare Commission), aim to foster high quality audits in which the clinical direction is provided through the appropriate national professional bodies and where management of the process, including project management and provision of IT, is undertaken by appropriate specialists.

The programmes are designed to support clinicians who wish to audit the quality of their care. The national audits provide benchmarking and comparative information via a quality-assured approach applying risk-adjustment (e.g. casemix adjustment) where necessary.

As well as providing feedback so that local clinicians and managers can identify where service improvements need to be made, further spurs to improve patient care may come in several ways:

- national reports summarise the key messages, often receiving considerable media attention when published
- since 2005/06, information about participation in the projects is being used to cross-check Provider Trusts' self-assessments against the DH's Core Standards, as part of the Healthcare Commission's new annual health check
- from 2006/07, findings from the projects will be used to help cross-check the declarations that Provider Trusts make about Developmental Standards.

Initially, a simple measure of participation in the head and neck cancer audit is being used in the assessment of Provider Trust declarations and measures of case ascertainment and data quality, to demonstrate appropriate levels of engagement in the audit, are being added into the assessment. The audit project team are now developing clinical indicators of the quality of care, which will be derived through the audit, which will also be used in the Healthcare Commission's assessment of Developmental Standards.

3.5.2 "NHS Plan" in England and "Designed to tackle cancer" in Wales, and cancer audit

The NHS quality agenda requires services to monitor quality of care delivered in a systematic way through clinical governance. Capacity to undertake clinical audit to monitor the quality of clinical care, specifically using national risk-adjusted clinical audit data, is a key component of clinical governance.

The Government is committed to introducing national comparative clinical audit to monitor clinical performance against agreed standards and indicators.

England

One of the key commitments of the NHS Cancer Plan[20] (which applies to England only), is to bring survival rates up to the best in Europe. Achievement of this objective will depend critically upon:

- ensuring that patients are diagnosed and treated without unnecessary delays
- ensuring that patients receive optimal treatment, especially the initial treatment package given after the diagnosis of cancer.

Implementation of the cancer waiting times dataset, (September 2003 for head and neck cancer) provides information on timeliness of treatment. However, current information and monitoring arrangements do not provide direct information on the appropriateness of treatment. To determine this, anonymised data on individual patients needs to be collected and analysed.

A cancer reform strategy is in development to build on the progress of the Cancer Plan. It recognises the new challenges and opportunities facing cancer, such as rising incidence, advances in medical technologies, new drugs and rising expectations amongst the public. An element of the strategy is clinical outcomes measurement.

Wales

One of the key commitments of the Assembly Government is to bring survival rates up to the best in Europe.

The Assembly's policy 'Designed to Tackle Cancer in Wales' requires all cancer teams using CaNISC to be participating routinely in national clinical audits and benchmarking with teams in the UK and Europe where possible by March 2008.

3.5.3 National Clinical Audit Support Programme (NCASP)

The National Clinical Audit Support Programme (NCASP), within The IC, now manages audits in heart disease, diabetes and cancer. The majority of this work is commissioned directly by the Healthcare Commission.

There are three established national clinical audits in cancer, covering head and neck, lung and bowel cancers and two new audits in oesophago-gastric cancer and in mastectomy and breast reconstruction. These audits, together with audits in coronary heart disease and diabetes, are commissioned by the Healthcare Commission.

In the National Head and Neck Cancer Audit, NCASP works directly with representatives of the British Association of Head and Neck Oncologists (BAHNO) who provide the clinical direction and specialist clinical input.

Following wide consultation on the audit proposals and subsequent system development and testing, the audit was formally launched in 2003 and has subsequently received data from Wales for the first time in 2006.

Following a review of its audit programme, the Healthcare Commission has now contracted to fund this and the other cancer audits until 2009.

3.6 Key policy reports in improving cancer care

The Calman-Hine report, *A Framework for Commissioning Cancer Services* published in 1995[21] identified inequities in service provision for cancer patients and the resultant variable outcomes. The report emphasised the importance of monitoring and auditing of the quality of service provision, a theme emphasised by the National Cancer Plan published by the Department of Health in 2000.[20]

This was also a central theme in the Welsh Assembly Government's 'Cancer Information Framework' published in 2000.[20] As a result of these reports, a National Cancer Data Set (NCDS)[22] was developed by The Information Centre for health and social care (IC) and Connecting for Health (CFH) in England and the Cancer Services Coordinating Group in Wales, to assist cancer service providers in the sharing of data across all healthcare boundaries, to support patient care and comparisons of cancer information.

The NCDS assists in assessing:

- the provision of high quality care for individual patients
- the delivery of clinical governance, ensuring that care received by groups of patients is in line with national guidance and achieves the best possible outcomes
- performance management, which ensures that national targets (e.g. for waiting times) are achieved
- public health and inequalities reduction
- monitoring of incidence trends, survival and mortality at a population level.

The latest versions of the dataset and supporting manuals can be found at: www.ic.nhs.uk (or for DAHNO Users www.DAHNO.com).

The importance of timely delivery of care has been enforced by the introduction of waiting time targets in England initially for referral to first appointment 'two week wait', and for head and neck cancer from 1 January 2006 from referral to first treatment (62 days) and from decision to treat to first treatment (31 days).

In Wales, a series of waiting time targets share similar themes of referral and treatment but are different in definition (See Appendix 9).

3.7 National Institute for Clinical Excellence (NICE) Improving Outcomes Guidance (IOG) for head and neck cancer

Clinical guidelines are recommendations by the National Institute for Clinical Excellence (NICE) on appropriate treatment and care of individuals with specific diseases and conditions within the NHS. They are based on best available evidence. Guidelines aim to help health professionals in their work, but they do not replace their knowledge and skills.

Good clinical guidelines aim to improve quality of healthcare. They can change processes of healthcare and improve outcomes by:

- providing recommendations for treatment and care of people by health professionals
- using them to develop standards to assess the clinical practice of individual health professionals
- using them to educate and train healthcare professionals
- helping patients to make informed decisions, and improve communication between patient, families and carers and health professional
- NICE commissioned the National Cancer Steering Group to develop service guidance on head and neck cancer for NHS use in England and Wales. The guidance was published in 2005 and provides recommendations for good practice that are based on best available evidence of clinical and cost effectiveness. The guidance can be found at: www.nice.org.uk/page.aspx?o=233550, and subsequently developed measures at: www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/Cancer.

The areas addressed include head and neck cancer, Cancer Networks and MDT's, referral, diagnosis and assessment, treatment services, post-treatment follow-up and care, prevention and awareness, patient centred care and palliative care.

In Wales,[23] National Standards for Head and Neck Cancer Services 2005 define the core aspects of the service that should be provided for cancer patients throughout Wales by March 2009. The standards are to be used in conjunction with other requirements for example, the National Institute for Clinical Excellence (NICE) recommendations.

Implementation of the Improving Outcomes Guidance (IOG) in England is expected by December 2008 and action plans from each of the thirty three Cancer Networks in England have been created. A peer review process[24] to assess levels of current compliance and future plans will commence in the next financial year.

3.8 The Healthcare Commission and annual health check

The long-term objective for the Healthcare Commission, as described above (Section 3.5.1), is to ensure that each level of the NHS and the public have access to accurate and complete risk-adjusted comparative clinical audit data. Participation will be used in the Healthcare Commission's annual health check of NHS Provider Trusts in England to support monitoring quality and performance against agreed clinical standards and benchmarks, whether contained in National Service Framework (NSFs), National Institute for Clinical Excellence (NICE) guidelines or other national guidance.

Outcome specific measures to be incorporated in the manual of measures and in developmental standards for the annual health check are currently in development. A measure of participation common to all NCASP audits will be included as well as DAHNO specific outputs.

In Wales, the Healthcare Strategy set out in Designed for Life requires that all cancer teams participate in all-Welsh clinical audit's by March 2008.

3.9 SIGN guidelines

These national guidelines from the Scottish Intercollegiate Guidelines Network on the diagnosis and management of head and neck cancer were published in 2006. They do not represent standards of care but aim to assist health professionals in clinical decision making, based on best available evidence as assessed by the SIGN group.[25]

3.10 Other stated / published clinical standards used as benchmarks

Standards are precise authoritative criteria to ensure a process is fit for purpose. They are created with co-operation of and consensus from professionals and patients, or general approval of, interested parties. Based on consolidated findings of evidence and experience, they are aimed at promoting optimum benefit as well as approval and sponsorship of a professional national body.

Health care standards allow the provision of a common set of requirements for care that apply to all healthcare organisations to ensure that health services are provided that are both safe and of an acceptable quality. Secondly they provide a framework for continuous improvement in the overall quality of care people receive. The ability to monitor and measure the delivery of care against a peer derived standard will lead to the driving up of quality of care and provides an important quality assurance framework as well as governance.

Standardisation improves efficiency by delivering service consistency. It aims to avoid geographic variation.

The complex multifaceted nature of head and neck cancer care pathways means that standards are an essential component for audit, bench-marking and accreditation, certification and designation of cancer provision.

In 2001, a consensus group of practising clinicians supported by BAHNO published practical care guidance for clinicians participating in the management of UK head and neck cancer patients.[1] The guidance proposed a series of quality objectives.

The consensus guidance from the British Association of Otolaryngologists and Head and Neck Surgeons throughout its iterations (1998 to 2002),[27] [28] [29] reviewed current standards, and sought to determine consensus standards of service delivery and aspects of care along the head and neck pathway to promote a common framework of delivery. The process was the result of extensive patient and carer discussion based on the South West Head and Neck Audits (SWAHN 1).[30] [31] [32] Where professional and patient / carer standards disagreed significantly, the patient / carer viewpoint was taken as the default position. No formal monitoring of the uptake or acceptance of these standards across England has occurred.

In 2001, the NHS sponsored a 'proposal generating event' consisting of multi-disciplinary head and neck groups from across England to describe what an ideal head and neck service would look like. This was used as a basis to develop the improving outcomes guidance subsequently published in 2005.

To update the standards defined following the SWAHN audit, the BAHNO council formed a small group to define current standards for the delivery of head and neck cancer care. The multi professional group reviewed current standards and felt that the standards defined from the SWAHN audit formed a good starting point for development. The standards were updated and will be sent for wider consultation before being presented to BAHNO council for approval. If accepted they will form a national set of standards for the delivery of head and neck cancer care, that will facilitate critical appraisal of the care pathway and provide information to support both local and national developments in this complex area of healthcare delivery.

The intention of the audit for the next Annual Report is to compare data submissions against agreed standards subject to BAHNO agreeing the standards.

4.0 DAHNO application infrastructure

4.1 DAHNO application

The head and neck cancer audit application (known as **DAHNO** - **D**ata for **H**ead and **N**eck **O**ncology) uses IBM Lotus Notes® and IBM Lotus Domino® as constituents for its software infrastructure. IBM Lotus Notes® and IBM Lotus Domino® are industry leading, client-server, collaborative document-management products incorporating robust security features, and have been widely adopted for use in the commercial sector.

Use of the DAHNO application requires connection to NHSnet. It is installed by an auto install CD with minimal local IT system changes required.

IBM Lotus Notes® allows documents to be defined for data entry and display and treats collections of documents as 'databases'. Each document can be populated with all the design elements familiar to web users.

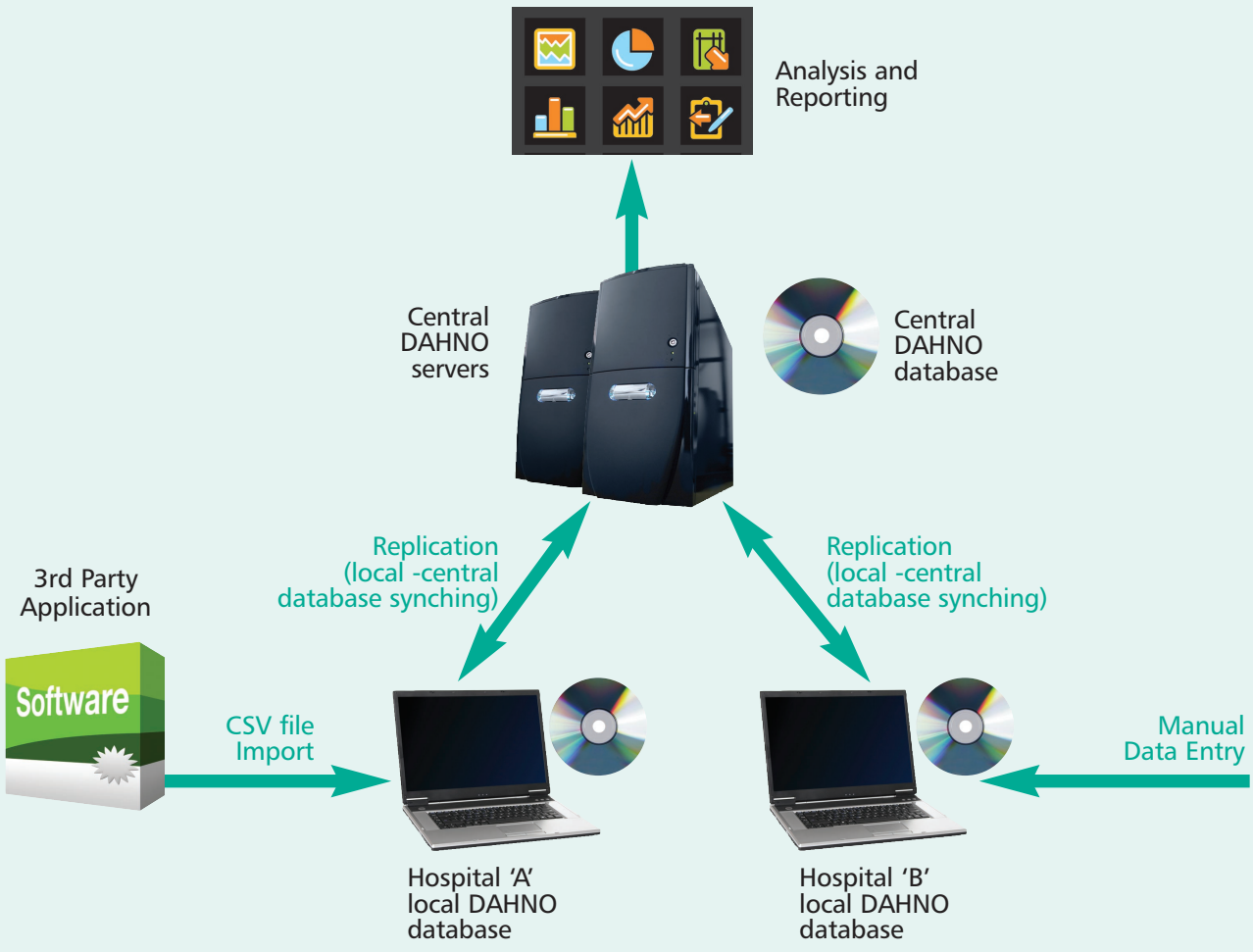
Each hospital accesses its own local encrypted replica of the DAHNO application database so that the DAHNO application response times are not subject to any network delays.

Opening a database allows users to see all documents to which they have authorised access and in turn allows creation of new documents (either by directly keying-in data or by importing data from a third party supplied data file) or editing of existing information.

Once data has been entered into the hospital's local DAHNO application database, the database is then synchronised with the central DAHNO application database so that data can be analysed, and subsequently reported on.

The application requirements and recommendations can be found in Appendix 4.

Figure 4.1.a: DAHNO Application Overview.



4.1.1 Data submission from Wales

Data from Wales was collected in a summary electronic patient record via the Cancer Network Information System Cymru (CaNISC), and collated and uploaded to the DAHNO application as a Comma Separated Value (CSV) file.

4.2 DAHNO application security and patient confidentiality

4.2.1 DAHNO application security

Security mechanisms are designed to ensure only authorised users access information on the DAHNO application database. Users only see records submitted by their own organisation (unless permission is given for them to view other organisations' data from other Provider Trusts and Cancer Networks), and published information contains only comparative analysis figures. Several levels of security are built in to the system:

- ID security: the DAHNO application is accessed through use of an IBM Lotus Notes® ID, and that ID can be set to expire or have its access terminated, thus preventing unauthorised users from accessing the system. A complex password is required to access the IBM Lotus Notes® ID (and thus, the DAHNO application itself) and that password can be set to expire after a given period forcing the user to change it regularly
- server security: the central (server-based) DAHNO database replica is also protected by server security so that no unauthorised persons can obtain access to it or replicate data to it
- application security: access to the IBM Lotus Notes® database is controlled by a database Access Control List (ACL). This ensures both non-repudiation (a user cannot deny that they have accessed data) and that users and organisations only have access to their own records. Users may be given 'read only' or editing rights. Users can delete records if they have the correct permissions and there are no child documents relating to that record.

The application is also encrypted so that if any unauthorised person were to somehow obtain the hard drive upon which the DAHNO application exists, they would also need an authorised ID file (and knowledge of its password) to access it.

All system database accesses are recorded in a system log file that can be audited in event of suspected security threats or data misuse.

4.2.2 Patient confidentiality

Audit data is subject to strict rules of confidentiality. The National Clinical Audit Support Programme (NCASP) continues to work with the Healthcare Commission and the Patient Information Advisory Group (PIAG) to ensure that support is provided under Section 60 of the Data Protection Act for the collection and use of patient identifiable data. All current NCASP audits have PIAG support.

Cancer centres send the data to the DAHNO application via a secure connection to the NHS secure network, (NHS Net), where it is securely stored on a highly encrypted national computer database. Once captured, the data is only accessible to people who store and analyse the data. Patients can choose to opt out of the audit, such that their details will not be stored or used for any purpose by the audit.

5.0 Methods and approaches

5.1 Methodology

A generic methodology in common with other National Clinical Audit Support Programme (NCASP) cancer audits was followed, to include the following items:

- establishment of, and agreement to, the main questions the project would address derived from the aims of the National Cancer Framework
- establishment of data items needed to answer the specified issues (a sub-set of the National Cancer Dataset, NCDS)
- agreement of a project plan and timetable (including funding issues, roles and responsibilities of partner organisations and process for recruitment and support of participating centre):
  - development of a model for the process(es) of local data collection, central collation and analysis (including issues of security and confidentiality, to meet Caldicott Guardian requirements)
  - development of methodology for quality assurance of data
  - development of interfaces and messages followed by notification of specifications to system suppliers, modification of software packages accordingly and rollout to users
  - definition of processes to oversee data collection, transmission and collation on a day-to-day basis
- responsibilities for data analysis and interpretation (including such issues as levels of access)
- reporting format, timing and procedures.

5.2 Clinical aspects

5.2.1 Inclusions in the head and neck cancer audit phase I

In planning and deploying the DAHNO application, it was recognised there was a need for local organisations to commit resources to enable regular and timely collection of data. The scope of the first phase, (by limiting collection to squamous cell carcinomas of the oral cavity and larynx), hoped to allow good case acquisition, whilst keeping the burden of data collection to manageable proportions. In later phases, it is envisaged that data from all tumour types and sub-sites will be collected.

Using the relevant the National Cancer Dataset (NCDS) elements, the DAHNO Project Team aimed to identify the following details from contributory centres:

- new primary cases of squamous cell head and neck carcinoma involving the larynx and oral cavity
- the ***patients diagnosed with head and neck cancer (larynx and oral cavity) by Cancer Network*** (and their component Provider Trusts and cancer centres) across England and Wales and their urgency of presentation (e.g. urgent cancer referral, routine referral etc), in each case to use a population denominator (or close) derived via the cancer registries. This is needed to reflect both workload and distribution of cases
- ***decompensation from comorbidity at diagnosis***
- whether management of cancer patients ***has been by an identified multi-disciplinary team and to agreed standards with equity of care and without undue delay***
- the ***primary treatment modality(ies) received (including adjuvant therapy) for larynx and oral cavity*** including surgical resection, radical and palliative radiotherapy, chemotherapy, specialist palliative care, and supportive care
- ***disease eradication***
- ***head and neck cancer specific mortality rate and age-specific corrected survival.***

Exclusions in the current phase of the head and neck cancer audit

Exclusions in phase I of the head and neck cancer audit are:

- cancers in anatomical cancer sites outside the larynx and oral cavity
- carcinoma in situ of the larynx and oral cavity
- non-squamous carcinomas and secondary carcinomas to the head and neck
- secondary treatment modalities for recurrent disease
- adverse events.

5.2.2 Casemix factors

The head and neck cancer audit examines key casemix factors in detail for the first time on a large scale. Data collection has historically been poor with regard to many of these factors which are crucial to the debate. The key factors considered are:

- age and sex
- comorbidity
- performance status
- stage at presentation and time of treatment decision.

Part of the NCDS development was to identify a robust, meaningful and user-friendly comorbidity scale. No such scale is universally accepted. The Adult Co-morbidity Evaluation Scale - ACE-27 (see Appendix 7) has been validated in both the United States of America (USA) and in Great Britain and has been applied to adults with head and neck cancer. A patient's self administered questionnaire is available and allows rapid collection and collation of an integer score (0,1,2,3).

Within the care pathway of patients with head and neck cancer, diagnostic services have a significant impact on timeliness both in diagnosing and treating cancer centres. They are key potential bottlenecks that determine the pace at which individuals can progress to commencement of treatment.

A questionnaire was distributed on joining the head and neck cancer audit, to assess local access to services as well as to specialist diagnostic and treatment services, such as the number of local Computerised Tomography (CT) and Magnetic Resonance Imaging (MRI) scanners, specialist radiologists, specialist histo-pathologists, surgeons, oncologists and palliative care consultants etc. The aim is to update this throughout future phases of the audit.

Putting all these aspects together, it should therefore be possible, for the first time, to determine at least the major likely causes of inter-district variations in treatment. This information can then be used by Cancer Networks to assist in supporting, developing and resourcing local head and neck cancer services.

5.3 Determining cancer centres: Provider Trusts managing head and neck cancer

Lead clinicians and managers from all thirty three English Cancer Networks were contacted at inception of the audit and asked to provide the names of NHS Provider Trusts that provide either diagnosis only or diagnosis and treatment to patients with head and neck cancer.

From the replies received, 190 cancer centres (and their associated Provider Trusts) were identified as contributing care to head and neck cancer patients. Subsequently the number of Provider Trusts submitting has reduced as some organisations have combined for purposes of submission or due to changes in the organisation of services. This will continue to be adjusted over time with any rationalisation of teams.

Throughout the current year each Cancer Network has been invited to attend sub-national training sessions to both encourage those yet to submit data, as well as to provide training and feedback to contributory individuals Provider Trusts and Cancer Networks.

In Wales, a presentation to the All Wales Head and Neck Cancer Group was made prior to the first submission of data by upload from the CaNISC system, and a list of organisations providing head and neck cancer care in Wales was provided.

5.4 Head and neck cancer audit rollout and maintenance

The detailed background to the early adopter and rollout phases have been described in the first annual report.[16]

In April 2004, a letter was sent to Provider Trust Chief Executives to ensure relevant people were aware of, and made necessary preparations to participate in the audit, which commenced a phased rollout during May to December in 2004 across England.

Following the First Annual Report, Provider Trusts who met a sufficient level of case submission received a focused local report, whilst those with a lower submission rate received a letter of thanks. Organisations and Networks who had not connected or submitted data received a further request to join the audit.

Non connection has been pursued by verbal, email and written contact to encourage participation, which will continue until we meet the Healthcare Commission expectations of 100 per cent participation.

5.5 DAHNO improvements rolled out in 2006

5.5.1 Improvements to the capturing and storing of pathology data

Improvements were made to the way pathology is captured and stored within the application such that every biopsy related data item has a corresponding biopsy reporting date.

5.5.2 Import to DAHNO

Support to users who encounter issues with data import to DAHNO via CSV files has been greatly improved by the introduction of centralised CSV import logging. Previously, all relevant logging data was only held on the user's machine, thus the NCASP DAHNO development team were not aware of a problem unless notified. User activity regarding imports can be proactively monitored. It is important that regular patterns of submission are established to ease the burden on support provision particularly close to the end of a data collection year.

5.5.3 Data Duplication

Duplicate data items arose due to patients being seen at more than one hospital were being assignation of different local Patient IDs. However, local patient IDs and hospitals have been removed from any document creation/searching indexes - resolving the issue.

5.5.4 Analysis of Data

Complex analysis of centralised DAHNO data has been greatly improved due to the introduction of a centralised analysis tool.

5.5.5 Hosting arrangements

Half-way through the reporting year, the Domino servers responsible for hosting the DAHNO application were moved to a new secure environment, and work carried out by the NCASP DAHNO development team ensured that this move was planned and executed in such a way, that minimised impact to users.

5.5.6 Linkage with the Office of National Statistics (ONS) for death data

A link was established between the application and the Office of National Statistics (ONS) so that a more accurate picture could be built for all the patients sampled, concerning any deaths that occurred within the reporting year. Batch details of deaths were entered into the DAHNO application, following a methodology developed by the Central Cardiac Audit Database (CCAD).

5.5.7 Imaging record-type error resolved

As stated in the previous DAHNO Annual Report, the anatomical examination field stored in the record-type responsible for storing imaging data, was initially created as a single entry field, and this led to the 'percentage having chest imaging by chest x-ray or CT scan prior to cancer careplan' output being invalidated (e.g. where a CT scan covered the neck and thorax, entering data for both cancer sites required two separate imaging records or the selection of only one cancer site). However, the field has been converted to a multiple-entry field, thus resolving the error and enabling the above output to be reported on, in this year's report.

5.6 Patient sample identification

Participating teams are asked to include prospectively all identifiable new primary cases of ***squamous carcinoma of the larynx and oral cavity (L+OC)*** seen in their institution / network as appropriate.

For larynx, this comprises: cancer sites ICD-1O C10.1, C32.0, C32.1, C32.2, C32.8, C32.9 (supraglottis (including lingual surface of epiglottis), glottis and subglottis) and for oral cavity: cancer sites C02-C06 (buccal mucosa, upper alveolus and gingiva, lower alveolus and gingiva, hard palate, tongue (dorsal and inferior) and floor of mouth).

These are identified from a range of sources:

- multi disciplinary teams (MDT) meetings
- urgent two week wait rule referrals and other clinic booking systems
- pathology reports
- hospital patient administration systems (PAS)
- death certificates (via cancer registries and / or Office of National Statistics (ONS)
- any other records maintained by members of the local head and neck cancer team.

5.7 Data standards

The audit dataset was submitted to the Information Standards Board (ISB) for approval in and received full operation standard approval in May 2006.

5.8 Priority outputs and rationale

The following are the major end points for analysis (and are further described in Appendix 4 as first priority outputs and shown in bold below):

1. Demographics and casemix **(outputs 1.1 – 1.6)**

   Number of patients with new head and neck primaries of the larynx and oral cavity (L+OC) per year by age, sex and stage:

   - percentage completion of staging and recording of stage prior to treatment planning by sub-site
   - percentage having pre-treatment measure of comorbidity and performance status
   - the effects of socio economic status on diagnosis, treatment and outcome.

2. Waiting intervals and source of referral: **(outputs 2.1 – 2.15)**

   - source of referral to specialist team including ratio of primary to secondary care, and of those, the number presenting under the two week rule.
   - waiting intervals from first symptom to first referral.
   - first referral to the specialist team to first out-patient visit.
   - first referral to diagnosis.
   - first referral to first definitive treatment.

   Within the pathway this will include:

   - interval from request to reporting of imaging (CT / MRI) contributing to pre-treatment staging and cancer care planning
   - the types of imaging performed
   - consideration of intervals from taking of specimens for histological examination to reporting.

3. Increasing the proportion of patients with squamous cell carcinoma of the larynx and oral cavity who receive appropriate specialist opinion and treatment. Examples **(outputs 3.1 – 3.12 larynx, outputs 4.1 – 4.12 oral cavity)** as measured by:

   - percentage of patients discussed in a multi-disciplinary team meeting prior to commencement of treatment, and assessment by a dietician and speech and swallowing therapist and appropriate dental assessment pre-treatment
   - percentage of confirmed squamous carcinoma of the larynx and oral cavity undergoing curative surgery by type of procedure and by age, stage, comorbidity and access to specialist surgical expertise
   - percentage of confirmed squamous carcinoma of the larynx and oral cavity undergoing resective surgery by type of clearance of surgical margins obtained, by sub-site
   - percentage of confirmed squamous carcinoma of the larynx and oral cavity undergoing radical radiotherapy by age, stage, comorbidity and access to clinical oncology expertise and linear accelerator / simulator time
   - dose and regimen (including continuous hyper fractionated accelerated radiotherapy (CHART), teletherapy and brachytherapy) of radical radiotherapy used in these patients by age, stage, comorbidity and access to Oncology expertise and equipment
   - percentage of confirmed squamous carcinoma of the larynx and oral cavity undergoing chemotherapy by age, stage, comorbidity and access to oncological expertise
   - percentage of confirmed squamous carcinoma of the larynx and oral cavity undergoing post-operative primary cancer site and neck irradiation
   - percentage of all squamous carcinoma of the larynx and oral cavity cancer cases referred to the specialist palliative care team.

4. Monitoring the improving outcomes of patient care: **(outputs 5.1 – 5.5)**

   - survival at 12, 24 and 60 months (extending to longer periods as the project progresses) in each of the sub-groups by centre
   - locoregional recurrence within one year and two years (by treatment and tumour type).

5. Clinical Trials: **(output 6.1)**

   - percentage of patients with squamous carcinoma of the larynx and oral cavity entered into national clinical trials following diagnosis.

6.0 Addressing the pitfalls

6.1 Cancer centre identification

Information on Provider Trusts that provide head and neck cancer care was identified by correspondence with Cancer Networks to draw up a definitive list. This highlighted a number of Provider Trusts who provide head and neck services but have their data submitted via an adjacent organisation. Records of participation were appropriately amended. Throughout the audit it remains important to maintain an up-to-date log of which institutions provide head and neck cancer care.

6.2 Design

The design for the DAHNO application was an iterative process between developers and the DAHNO Project Team. The early adopters phase identified a number of errors in both content and presentation and these led to application modifications on and subsequent updating of support manuals. The diligence of the early adopters must be acknowledged.

Improvements have been made to the application over the last year, including: the accommodation of hospitals submitting part or all of the patient pathway on behalf of another hospital, a centralised data analysis tool, and improvements to the data import process (including adding resective and diagnostic pathology to the import suite).

Investigations are currently underway to further improve the application design with a view to making it more efficient and easier to use and install (including centralising the application, and making it browser-accessible).

6.3 Data submission

Data can be submitted to the DAHNO application via direct data entry, which accounts for about two thirds of the data, or by uploading from a local third party system. Data submission by uploading from third party systems requires the construction of CSV export files. Producing the CSV files for the first time is a tedious process, but once established, it provides a continuous means for submission. The file contains data in a strict sequence and set-up. The DAHNO Project Team have found problems (e.g. the automatic addition of an additional column) with the export functions of some suppliers' systems and will continue to work with them to try to facilitate the transfer of data.

Improved error reporting, and centralised import logs have already been implemented, resulting in both the user and the helpdesk being better placed to solve any data-related import issues.

6.4 Comprehensive submission

From the log of Provider Trusts providing head and neck cancer care, direct contact from the DAHNO Project Team has been made to establish reasons for both non connection and non submission. The DAHNO Project Team, in partnership with the Healthcare Commission, Cancer Networks and head and neck professional bodies, will continue to encourage all organisations that are yet to submit any data to achieve this during 2007.

6.5 Submission completeness

Continuing analysis has demonstrated variability in record completeness between cancer centres and between records. A centralised reporting facility has been implemented which provides better identification of areas for improvement, for users to raise completeness. Work is currently underway to provide a set of web-accessible reports that will highlight both completeness and a selection of nationally-compared, key outputs.

Regular workshops will focus on amplifying both the processes of data collection and common areas of poor quality and completeness.

6.6 Analysis

The analysis for annual reports has proved to be a complex task, and is undertaken by a partnership of the cancer registries working with the DAHNO application developer. Numerator and denominator definition has iteratively supported this, and a methodology is established for consistent future comparisons. For future reports, it will remain a challenge to analyse data by Cancer Network, particularly where boundaries and patient treatment pathways may vary, and to understand its limitations and interpretation.

6.7 Data cleansing

Within the DAHNO application, data cleansing, where otherwise meaningless or unrecognised values can be automatically corrected during the import process to reflect valid data entries, has yet to be applied.

7.0 Statistical methods used for data analysis

The presented information is an analysis of a sample of larynx cancer and oral cancer cases from hospital Provider Trusts across England and Wales.

Most of the reported measures are either a count of cases or a percentage of total recorded cases. Notes accompanying each measure seek to make the basis of the calculations clear.

The interpretation of the results must take into consideration the incomplete ascertainment of the cohort; not all incident cases in England and Wales have been entered onto the system, and many of those cases that are recorded have data items which have not been entered.

- Counts are the totals number of records (usually of patients) in the DAHNO application data extract with a specific record value, or in some cases a count of records with a recorded value.
- The calculation of percentages involves a count and a denominator. The choice of denominator is complicated by incompleteness. For certain measures the selected denominator is the total number of registrations, for others it has been more appropriate to use the number of registrations with any recorded value for a particular data item.

The quality of any data analysis is dependent upon the ascertainment, completeness and accuracy of the data submitted. Analysis is based purely on the data submitted to the DAHNO application by contributing Provider Trusts. It is important to recognise that because some records are incomplete, the published information is based on fewer than the total number of registered cases. Particularly vulnerable are the interval calculations, for instance, 8.5.4 ***The Interval from referral to first appointment, broken down by "Two Week Wait" referrals and others;*** if a record has either of the two dates or referral details missing, that record cannot contribute to the chart.

Data is presented as a simple description of data gathered during work-in-progress. As the quality and quantity of data improves, more sophisticated analyses will become possible.

The data for analysis was extracted from the DAHNO application as a collection of text files (CSV format). Analysis was carried out using Stata® 8.1, Microsoft® Access 2000 and Microsoft® Excel 2000.

8.0 Findings

8.1 Introduction

The following analysis was performed by the cancer registries on data extracted from the DAHNO application database in accordance with the Data Analysis for the Annual Report Specification v0.9 November 2006, supplied to the cancer registries by the DAHNO Project Team. The data extract period includes patient records with a 'date of diagnosis' between 1 October 2005 and 31 October 2006 inclusive.

8.2 Analysed data

Over 1,400 patient diagnoses have been included in the analysis. This has increased by approximately 50 per cent from the first DAHNO Annual Report. For the first time data has been included from Wales. If all estimated cases had been collected, the total would have exceeded 2,900. The information presented in this report is, therefore, a snapshot of the total population. Figure 8.2.a shows an overview of data collected for larynx and oral cavity cancer for cases with data of diagnosis between 1 October 2005 and 31 October 2006.

A considerable rise in case ascertainment is needed in future iterations of the audit to ensure a comprehensive reflection of current English and Welsh head and neck cancer management.

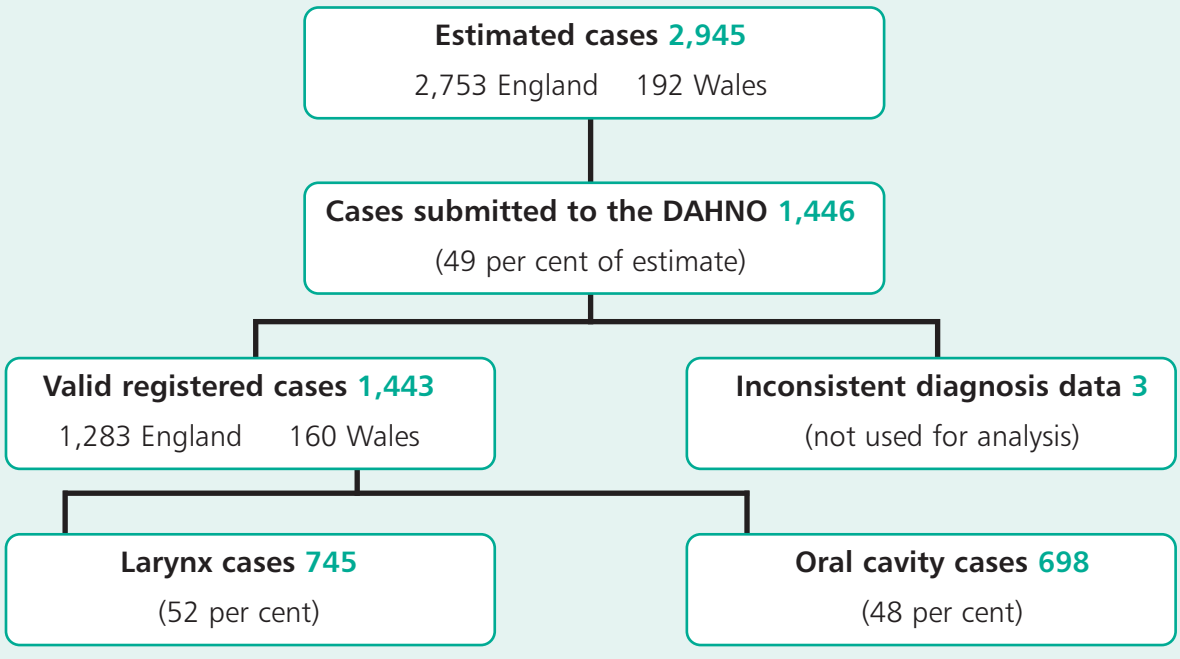
As this is a continuous audit with annual reporting years, inevitably some patients will complete the treatment phase of their pathway beyond the reporting year. A review of new cases with a diagnosis date prior to 1 October 2005, shows that contributors have added a further 367 cases. Future reports will seek to look cumulatively beyond the reporting year. Users are encouraged to get both diagnostic and treatment data as close as possible to the point of care delivery.

8.3 Where head and neck cancer care happens

1,446 cases were presented for analysis. 1,443 cases were registered with a date of diagnosis between 1 October 2005 and 31 October 2006 into DAHNO. These comprised 745 (52 per cent) laryngeal cancers and 698 (48 per cent) oral cavity cancers. A breakdown of registrations by anatomic sub-site is included in Figure 8.3.1a.

Three cases were excluded because of inconsistent diagnosis data.

Figure 8.2.a: Analysed data



8.3.1 Number of patients registered with new head and neck primaries of the larynx and oral cavity

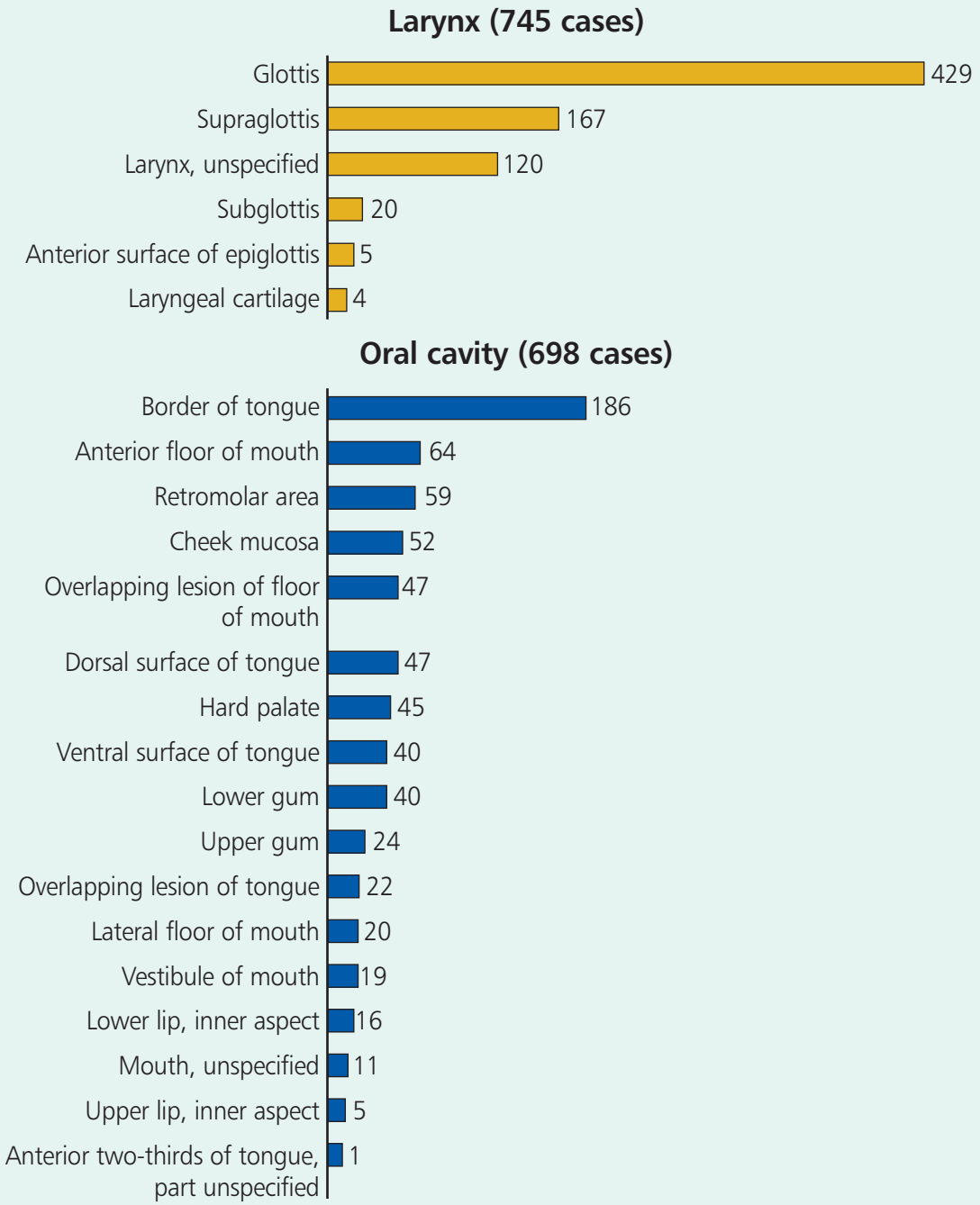
Figure 8.3.1.a: Number of patients registered with new head and neck primaries of the larynx and oral cavity

Number of patients registered by Site

	Site	Total
Larynx	Glottis	429
	Supraglottis	167
	Larynx, unspecified	120
	Subglottis	20
	Anterior surface of epiglottis	5
	Laryngeal cartilage	4
	Larynx Total	**745**
Oral cavity	Border of tongue	186
	Anterior floor of mouth	64
	Retromolar area	59
	Cheek mucosa	52
	Overlapping lesion of floor of mouth	47
	Dorsal surface of tongue	47
	Hard palate	45
	Ventral surface of tongue	40
	Lower gum	40
	Upper gum	24
	Overlapping lesion of tongue	22
	Lateral floor of mouth	20
	Vestibule of mouth	19
	Lower lip, inner aspect	16
	Mouth, unspecified	11
	Upper lip, inner aspect	5
	Anterior two-thirds of tongue, part unspecified	1
	Oral Cavity Total	**698**
	Total	**1,443**

Figure 8.3.1.b: Number of patients registered with new head and neck primaries of the larynx and oral cavity

Registrations to DAHNO October 2005 to October 2006



In larynx, as expected, glottic cancers predominate, (57 per cent), with 23 per cent occurring in the supraglottis. This was a similar distribution to that seen previously. 'Larynx NOS' (not otherwise specified) represents those cancers which involve multiple sub-sites, and are also referred to as transglottic tumours, or it reflects failure to delineate the site of tumour origin.

The number of subglottic tumours appears higher than expected (2.7 per cent compared to 1.7 per cent of all Office of National Statistics (ONS) registrations) but most likely reflects a sampling bias. It is important that cancer site information is correctly entered to allow true comparison of sub-site outcomes and inter regional differences.

In oral cavity, anterior and lateral tongue are the most common cancer sites, (36 per cent), with a more even distribution amongst the remaining sub-sites. The hard palate (6 per cent compared to 2 per cent of all ONS registrations) appeared to be over represented. Eleven records included in 'unspecified oral cavity' have no specific cancer site code record. This was a similar distribution to that seen previously.

8.3.2 Estimate of total number of patients with new head and neck primaries of the larynx and oral cavity in the index period

The following figure includes an estimate of the expected number of cases of larynx and oral cavity cancers per year in England and Wales. The estimates for English Cancer Networks are those published in the first DAHNO Annual Report.[16] This data was used to estimate the maximum number of registrations the head and neck cancer audit might expect during the period covered by this report (13 months) in each English Cancer Network and Wales.

The estimate for Wales was calculated by assuming that the ratio of the English estimate to the ONS total cases of head and neck cancer 2004[1] is the same as the ratio of the Welsh estimate to the Welsh Cancer Intelligence Unit total cases of head and neck cancer 2004[2].

The calculation of theses estimates used two sources of information; the ONS compilation of registrations 2002 and the total of first attendances at hospital summarised by the cancer waiting time group and Cancer Network (1999-2001) compiled from cancer registry data.

The cancer registry data is a good estimate of new patients, which allows for incident cases not-attending at hospital. It does include a wider selection of tumour sites than oral cavity and larynx. The ONS all registrations data was used to calculate the proportion of all head and neck cancers that are categorised as oral cavity or larynx. Although Cancer Networks serve a geographically defined population, they may also see cross border referrals.

Figure 8.3.2.a: Estimate of total number of patients with new head and neck primaries of the larynx and oral cavity in the index period

Cancer Network	DAHNO registrations	estimate for 13 months	DAHNO registrations as per cent of estimate
Mid Trent Cancer Network	139	92	151
Sussex Cancer Network	67	54	124
Derby/Burton Cancer Network	45	38	118
Cancer Care Alliance of Teesside, South Durham and North Yorkshire	65	58	112
Peninsula Cancer Network	113	103	110
Norfolk and Waveney Cancer Network	39	39	100
Pan Birmingham Cancer Network	99	108	92
Leicestershire, Northamptonshire and Rutland Cancer Network	62	70	89
Arden Cancer Network	37	46	80
Northern Cancer Network	112	141	79
Yorkshire Cancer Network	93	141	66
Dorset Cancer Network	26	46	57
Thames Valley Cancer Network	63	110	57
Mid Anglia Cancer Network	25	46	54
Avon, Somerset and Wiltshire Cancer Services	50	97	52
Surrey, West Sussex and Hampshire Cancer Network	23	51	45
North Trent Cancer Network	41	94	44
Mount Vernon Cancer Network	21	51	41
Humber and Yorkshire Coast Cancer Network	23	57	40
South West London Cancer Network	31	85	36
South Essex Cancer Network	10	31	32
3 Counties Cancer Centre Network	14	57	25
Greater Manchester and Cheshire Cancer Network	40	202	20
Kent and Medway Cancer Network	19	93	20
Lancashire and South Cumbria Network	16	102	16
Merseyside and Cheshire Network	10	142	7
Black Country Cancer Network	0	43	0
Central South Coast Cancer Network	0	120	0
North East London Cancer Network	0	59	0
North London Cancer Network	0	76	0
North West Midlands Network	0	61	0
South East London Cancer Network	0	74	0
West Anglia Cancer Network	0	83	0
West London Cancer Network	0	83	0
ENGLAND	**1,283**	**2,753**	**47**
WALES	**160**	**192**	**83**
TOTAL	**1,443**	**2,945**	**49**

Networks are shown as defined at the start of the index period October 2005.

Black Country Cancer Network and North West Midland Cancer Network merged during the year to form the Greater Midlands Cancer Network.

8.3.3 Submission by Network and Provider Trust of patients with new head and neck primaries of the larynx and oral cavity in the index period

Figure 8.3.3.a: Submission by Network and Provider Trust of patients with new head and neck primaries of the larynx and oral cavity in the index period

Cancer Network	Submitting Provider Trust to DAHNO	Larynx	Oral Cavity	Total
3 Counties Cancer Centre Network	Gloucestershire Hospitals NHS Trust	1	1	2
	Hereford Hospitals NHS Trust	6	6	12
	Total	**7**	**7**	**14**
Arden Cancer Network	South Warwickshire General Hospitals NHS Trust	3	0	3
	University Hospitals Coventry and Warwickshire NHS Trust	15	19	34
	Total	**18**	**19**	**37**
Avon, Somerset and Wiltshire Cancer Services	North Bristol NHS Trust	33	10	43
	Taunton and Somerset NHS Trust	5	2	7
	Total	**38**	**12**	**50**
Cancer Care Alliance of Teesside, South Durham and North Yorkshire	South Tees Hospitals NHS Trust	36	29	65
	Total	**36**	**29**	**65**
Derby/Burton Cancer Network	Derby Hospitals NHS Foundation Trust	19	26	45
	Total	**19**	**26**	**45**
Dorset Cancer Network	Poole Hospitals NHS Trust	8	8	16
	Royal Bournemouth and Christchurch Hospitals NHS Trust	0	1	1
	West Dorset General Hospitals NHS Trust	2	7	9
	Total	**10**	**16**	**26**
Greater Manchester and Cheshire Cancer Network	Christie Hospital NHS Trust	6	10	16
	Pennine Acute Hospitals NHS Trust	0	1	1
	Salford Royal Hospitals NHS Trust	7	0	7
	Tameside and Glossop Acute Services NHS Trust	6	10	16
	Total	**19**	**21**	**40**
Humber and Yorkshire Coast Cancer Network	Hull and East Yorkshire Hospitals NHS Trust	17	6	23
	Total	**17**	**6**	**23**
Kent and Medway Cancer Network	Medway NHS Trust	7	12	19
	Total	**7**	**12**	**19**
Lancashire and South Cumbria Network	East Lancashire Hospitals NHS Trust	1	0	1
	Lancashire Teaching Hospitals NHS Foundation Trust	12	3	15
	Total	**13**	**3**	**16**
Leicestershire, Northamptonshire and Rutland Cancer Network	Northampton General Hospital NHS Trust	5	14	19
	University Hospitals of Leicester NHS Trust	17	26	43
	Total	**22**	**40**	**62**
Merseyside and Cheshire Network	Countess of Chester Hospital NHS Trust	2	6	8
	St Helens and Knowsley Hospitals NHS Trust	1	0	1
	Wirral Hospital NHS Trust	1	0	1
	Total	**4**	**6**	**10**
Mid Anglia Cancer Network	Essex Rivers Healthcare NHS Trust	8	7	15
	Ipswich Hospital NHS Trust	2	8	10
	Total	**10**	**15**	**25**
Mid Trent Cancer Network	Nottingham City Hospital NHS Trust	21	18	39
	Nottingham University Hospital NHS Trust	20	20	40
	Sherwood Forest Hospital NHS Trust	7	2	9
	United Lincolnshire Hospitals NHS Trust	27	24	51
	Total	**75**	**64**	**139**
Mount Vernon Cancer Network	Luton and Dunstable Hospital NHS Trust	14	7	21
	Total	**14**	**7**	**21**
Norfolk and Waveney Cancer Network	James Paget Healthcare NHS Trust	4	4	8
	Norfolk and Norwich University Hospital NHS Trust	22	9	31
	Total	**26**	**13**	**39**

Figure 8.3.3.a: continued...

Cancer Network	Submitting Provider Trust to DAHNO	Larynx	Oral Cavity	Total
North Trent Cancer Network	Chesterfield and North Derbyshire Royal Hospital NHS Trust	0	9	9
	Doncaster and Bassetlaw Hospitals NHS Trust	22	2	24
	Sheffield Teaching Hospitals NHS Trust	4	4	8
	Total	**26**	**15**	**41**
Northern Cancer Network	City Hospitals Sunderland NHS Trust	14	7	21
	North Cumbria Acute Hospitals NHS Trust	9	10	19
	The Newcastle Upon Tyne Hospitals NHS Trust	39	33	72
	Total	**62**	**50**	**112**
Pan Birmingham Cancer Network	Heart of England NHS Foundation Trust	2	0	2
	Sandwell and West Birmingham Hospitals NHS Trust	12	0	12
	University Hospital Birmingham NHS Trust	30	55	85
	Total	**44**	**55**	**99**
Peninsula Cancer Network	Northern Devon Healthcare NHS Trust	2	2	4
	Plymouth Hospitals NHS Trust	21	14	35
	Royal Cornwall Hospitals NHS Trust	15	12	27
	Royal Devon and Exeter Healthcare NHS Trust	7	16	23
	South Devon Healthcare NHS Trust	10	14	24
	Total	**55**	**58**	**113**
South Essex Cancer Network	Southend Hospital NHS Trust	5	5	10
	Total	**5**	**5**	**10**
South West London Cancer Network	St George's Marsden Hospital NHS Trust	1	0	1
	The Royal Marsden Hospital NHS Trust	13	17	30
	Total	**14**	**17**	**31**
Surrey, West Sussex and Hampshire Cancer Network	Royal Surrey County Hospital NHS Trust	9	14	23
	Total	**9**	**14**	**23**
Sussex Cancer Network	Brighton and Sussex University Hospitals NHS Trust	15	18	33
	East Sussex Hospitals NHS Trust	18	7	25
	Worthing and Southlands Hospitals NHS Trust	3	6	9
	Total	**36**	**31**	**67**
Thames Valley Cancer Network	Heatherwood and Wexham Park Hospitals NHS Trust	7	1	8
	Oxford Radcliffe Hospital NHS Trust	24	31	55
	Total	**31**	**32**	**63**
Yorkshire Cancer Network	Bradford Hospitals NHS Trust	21	30	51
	York Health Services NHS Trust	19	23	42
	Total	**40**	**53**	**93**
	England Total	**657**	**626**	**1,283**
North Wales Cancer Network	Conway and Denbighshire NHS Trust	6	6	12
	North East Wales NHS Trust	3	8	11
	North West Wales NHS Trust	8	10	18
	Total	**17**	**24**	**41**
South East Wales Cancer Network	Gwent Healthcare NHS Trust	21	3	24
	North Glamorgan NHS Trust	4	1	5
	Pontypridd and Rhonda NHS Trust	1	0	1
	Velindre Hospital Trust	13	6	19
	Cardiff and Vale NHS Trust	11	17	28
	Total	**50**	**27**	**77**
South West Wales Cancer Network	Bro Morgannwg NHS Trust	4	3	7
	Carmarthenshire NHS Trust	5	0	5
	Pembrokeshire and Derwen NHS Trust	3	0	3
	Swansea NHS Trust	9	18	27
	Total	**21**	**21**	**42**
	Wales Total	**88**	**72**	**160**
	England and Wales Total	**745**	**698**	**1,443**

Networks are shown as defined at the start of the index period October 2005.

Black Country Cancer Network and North West Midland Cancer Network merged during the year to form the Greater Midlands Cancer Network.

- 1,443 patients, of a theoretical maximum total of 2,945 patients have been registered (49 per cent) to the audit.
- 26 out of 33 Cancer Networks have entered at least one patient onto the DAHNO application. The minimum contribution from any submitting network was 10 cases.
- At individual Provider Trust level a number of organisations who had previously contributed high levels of registration were unable to achieve this in 2005 – 2006. For some this was a loss of data entry resource and others technical reasons in the upload of information from third party systems.
- The DAHNO application can receive data by either direct data entry (two-thirds of submissions) or by the use of a CSV upload facility (one-third of submissions). A number of organisations that collect data on in-house / third party systems have not taken the opportunity to contribute as yet. The DAHNO helpdesk is available to help users contribute by this means, with both technical and practical advice. The project development team continue to try and simplify the upload process.
- Data from Wales was initially collected in the National Summary Electronic Cancer Patient Report (CaNISC) system and uploaded via a CSV export into DAHNO.
- The best performing Cancer Networks have managed to achieve high levels of registration. These have benefited from good organisation, shared learning and the investment by hospital Provider Trusts in data collection personnel.
- The multi-disciplinary team (MDT) meeting is a key focal point for data collection as the correct members of the team are assembled.

8.3.4 Submission by Network and Provider Trust of patients with new head and neck primaries of the larynx and oral cavity in the index period, where cases had recorded T and N staging category

Counts of cases with recorded T and N staging by hospital of diagnosis:

- of 1,443 patients, who have been registered to the audit, only 776 (53.8 per cent) contained T and N pre treatment staging category information
- at least one Network held staging information in a third party system but was unable to upload this information
- there is a wide variation between Networks in the quantity of staging information submitted.

Recording cancer site and accurate stage is a key medical responsibility, with best practice suggesting that this should be clearly documented and captured at the MDT. Staging remains a key influence on outcome. It is important that this improves to achieve 100 per cent of cases staged in any high quality database collection, to allow valid comparisons to be made.

Figure 8.3.4.a: Submission by Network and Provider Trust of patients with new head and neck primaries of the larynx and oral cavity in the index period, where cases had recorded T and N staging category

Cancer Network	Submitting Provider Trust to DAHNO	Cases submitted where T and N recorded	Total
3 Counties Cancer Centre Network	Gloucestershire Hospitals NHS Trust	0	2
	Hereford Hospitals NHS Trust	0	12
	Total	**0**	**14**
Arden Cancer Network	South Warwickshire General Hospitals NHS Trust	2	3
	University Hospitals Coventry and Warwickshire NHS Trust	0	34
	Total	**2**	**37**
Avon, Somerset and Wiltshire Cancer Services	North Bristol NHS Trust	12	43
	Taunton and Somerset NHS Trust	5	7
	Total	**17**	**50**
Cancer Care Alliance of Teesside, South Durham and North Yorkshire	South Tees Hospitals NHS Trust	0	65
	Total	**0**	**65**
Derby/Burton Cancer Network	Derby Hospitals NHS Foundation Trust	42	45
	Total	**42**	**45**
Dorset Cancer Network	Poole Hospitals NHS Trust	14	16
	Royal Bournemouth and Christchurch Hospitals NHS Trust	0	1
	West Dorset General Hospitals NHS Trust	5	9
	Total	**19**	**26**
Greater Manchester and Cheshire Cancer Network	Christie Hospital NHS Trust	11	16
	Pennine Acute Hospitals NHS Trust	0	1
	Salford Royal Hospitals NHS Trust	0	7
	Tameside and Glossop Acute Services NHS Trust	0	16
	Total	**11**	**40**
Humber and Yorkshire Coast Cancer Network	Hull and East Yorkshire Hospitals NHS Trust	0	23
	Total	**0**	**23**
Kent and Medway Cancer Network	Medway NHS Trust	8	19
	Total	**8**	**19**
Lancashire and South Cumbria Network	East Lancashire Hospitals NHS Trust	0	1
	Lancashire Teaching Hospitals NHS Foundation Trust	5	15
	Total	**5**	**16**
Leicestershire, Northamptonshire and Rutland Cancer Network	Northampton General Hospital NHS Trust	5	19
	University Hospitals of Leicester NHS Trust	38	43
	Total	**43**	**62**
Merseyside and Cheshire Network	Countess of Chester Hospital NHS Trust	0	8
	St Helens and Knowsley Hospitals NHS Trust	1	1
	Wirral Hospital NHS Trust	1	1
	Total	**2**	**10**
Mid Anglia Cancer Network	Essex Rivers Healthcare NHS Trust	7	15
	Ipswich Hospital NHS Trust	8	10
	Total	**15**	**25**
Mid Trent Cancer Network	Nottingham City Hospital NHS Trust	21	39
	Nottingham University Hospital NHS Trust	35	40
	Sherwood Forest Hospital NHS Trust	7	9
	United Lincolnshire Hospitals NHS Trust	21	51
	Total	**84**	**139**
Mount Vernon Cancer Network	Luton and Dunstable Hospital NHS Trust	15	21
	Total	**15**	**21**
Norfolk and Waveney Cancer Network	James Paget Healthcare NHS Trust	3	8
	Norfolk and Norwich University Hospital NHS Trust	14	31
	Total	**17**	**39**

Figure 8.3.4.a: continued...

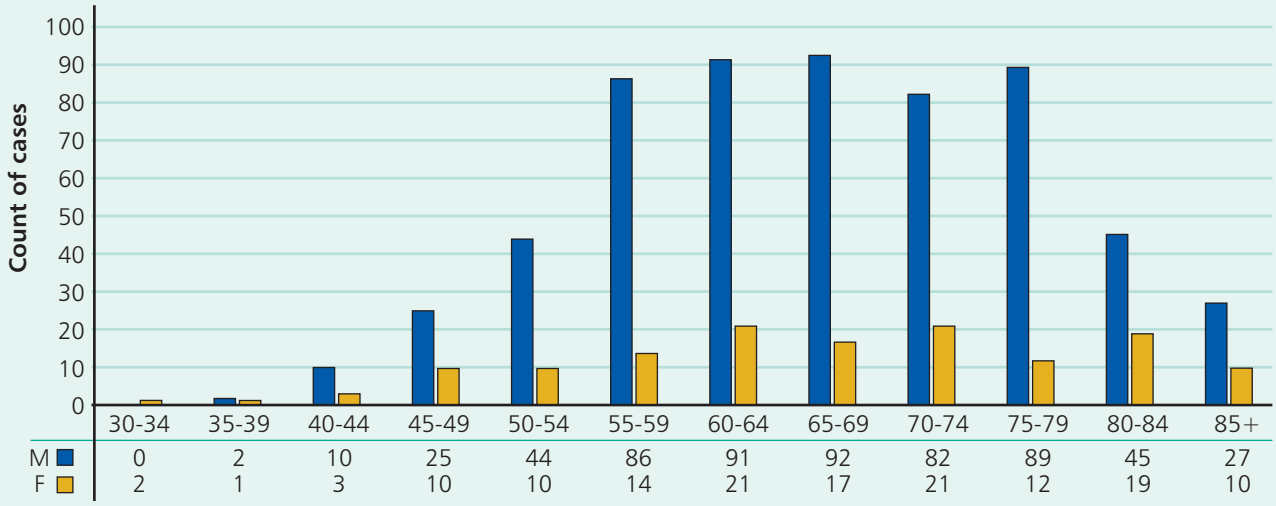
Cancer Network	Submitting Provider Trust to DAHNO	Cases submitted where T and N recorded	Total
North Trent Cancer Network	Chesterfield and North Derbyshire Royal Hospital NHS Trust	0	9
	Doncaster and Bassetlaw Hospitals NHS Trust	22	24
	Sheffield Teaching Hospitals NHS Trust	4	8
	Total	**26**	**41**
Northern Cancer Network	City Hospitals Sunderland NHS Trust	16	21
	North Cumbria Acute Hospitals NHS Trust	17	19
	The Newcastle Upon Tyne Hospitals NHS Trust	67	72
	Total	**100**	**112**
Pan Birmingham Cancer Network	Heart of England NHS Foundation Trust	0	2
	Sandwell and West Birmingham Hospitals NHS Trust	2	12
	University Hospital Birmingham NHS Trust	83	85
	Total	**85**	**99**
Peninsula Cancer Network	Northern Devon Healthcare NHS Trust	3	4
	Plymouth Hospitals NHS Trust	5	35
	Royal Cornwall Hospitals NHS Trust	0	27
	Royal Devon and Exeter Healthcare NHS Trust	23	23
	South Devon Healthcare NHS Trust	23	24
	Total	**54**	**113**
South Essex Cancer Network	Southend Hospital NHS Trust	10	10
	Total	**10**	**10**
South West London Cancer Network	St George's Marsden Hospital NHS Trust	1	1
	The Royal Marsden Hospital NHS Trust	24	30
	Total	**25**	**31**
Surrey, West Sussex and Hampshire Cancer Network	Royal Surrey County Hospital NHS Trust	18	23
	Total	**18**	**23**
Sussex Cancer Network	Brighton and Sussex University Hospitals NHS Trust	18	33
	East Sussex Hospitals NHS Trust	14	25
	Worthing and Southlands Hospitals NHS Trust	3	9
	Total	**35**	**67**
Thames Valley Cancer Network	Heatherwood and Wexham Park Hospitals NHS Trust	0	8
	Oxford Radcliffe Hospital NHS Trust	28	55
	Total	**28**	**63**
Yorkshire Cancer Network	Bradford Hospitals NHS Trust	22	51
	York Health Services NHS Trust	38	42
	Total	**60**	**93**
	England Total	**721**	**1,283**
North Wales Cancer Network	Conway and Denbighshire NHS Trust	1	12
	North East Wales NHS Trust	0	11
	North West Wales NHS Trust	3	18
	Total	**4**	**41**
South East Wales Cancer Network	Gwent Healthcare NHS Trust	16	24
	North Glamorgan NHS Trust	3	5
	Pontypridd and Rhonda NHS Trust	0	1
	Velindre Hospital Trust	3	19
	Cardiff and Vale NHS Trust	19	28
	Total	**41**	**77**
South West Wales Cancer Network	Bro Morgannwg NHS Trust	3	7
	Carmarthenshire NHS Trust	0	5
	Pembrokeshire and Derwen NHS Trust	3	3
	Swansea NHS Trust	4	27
	Total	**10**	**42**
	Wales Total	**55**	**160**
	England and Wales Total	**776**	**1,443**

8.4 Who receives the care – demography, casemix and socio economic status

8.4.1 Age and sex distributions of registrations

Larynx

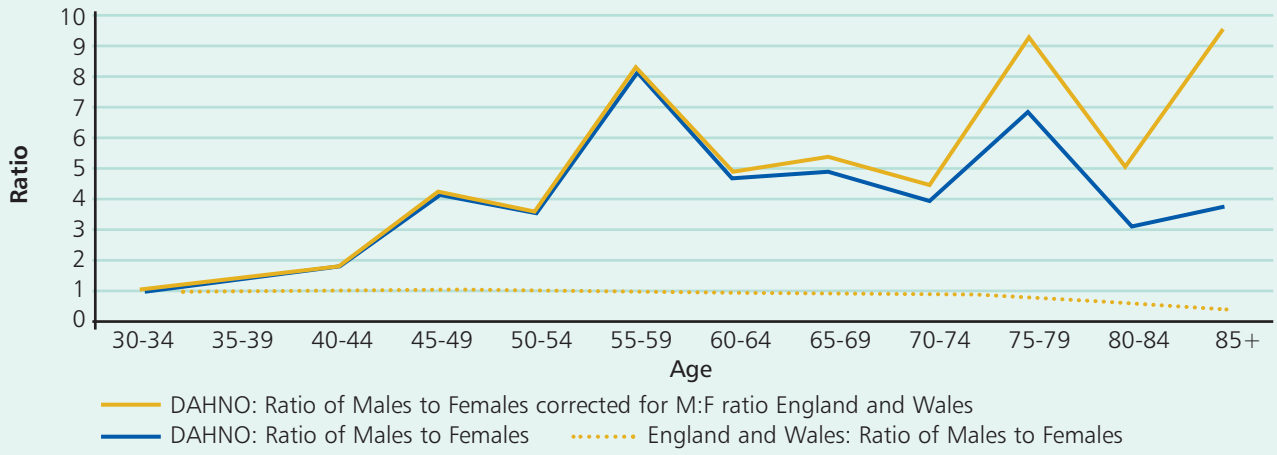
Figure 8.4.1.a: Larynx Cancer; Registration counts by age and sex



9 cases had unrecorded gender, aged between 55 and 80; 1 male case had unrecorded date of birth

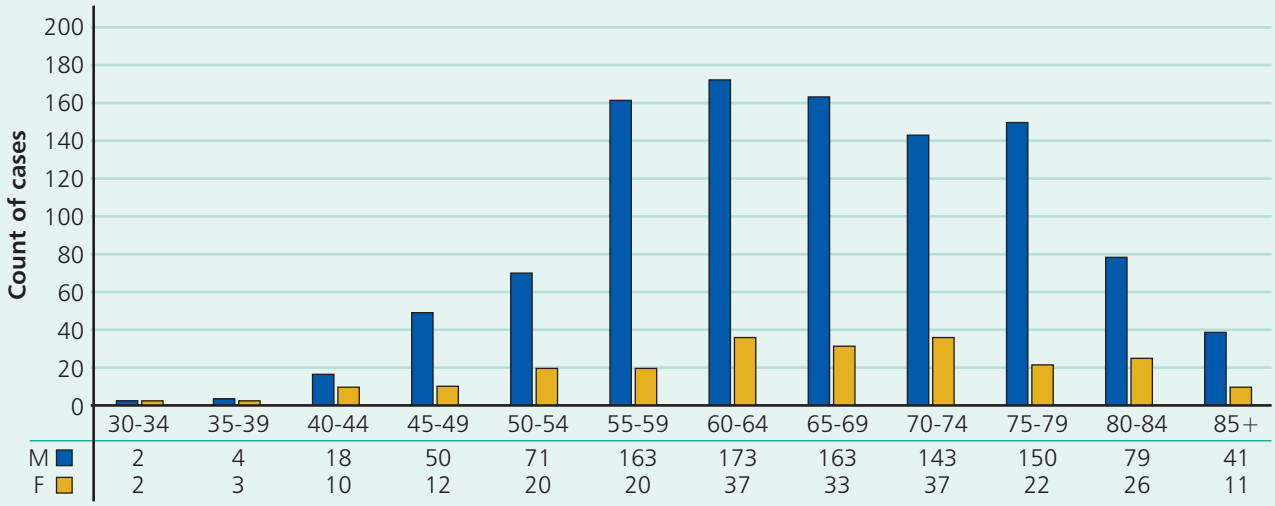
- 80 per cent of larynx cancer patients were male.
- 7 per cent were under 50 years of age.
- The median age for males was 67 years and 68 years for females.
- 7 per cent of male cases were under the age of 50.
- 22 per cent were aged over 75.
- 11 per cent of female cases were under the age of 50.
- 27 per cent were aged over 75.
- 1 case was under the age of 20.
- DAHNO registrations are broadly in line with ONS which reports the rate of laryngeal cancer peaking in the 75 to 79 age group for both males and females.

Figure 8.4.1.b: Ratio of male to female registrations larynx cancer compared with ratio of males to females in England and Wales, January 2004 to October 2006



- The ratio of male to female laryngeal cancers exceeds the ratio of males to females in England and Wales by a factor of approximately 5 beyond the age of 45 years.
- The risk of laryngeal cancer is approximately 5 times greater in males than in females over 45 years of age.

Figure 8.4.1.c: Larynx Cancer; Registration Counts by age and sex, January 2004 to October 2006

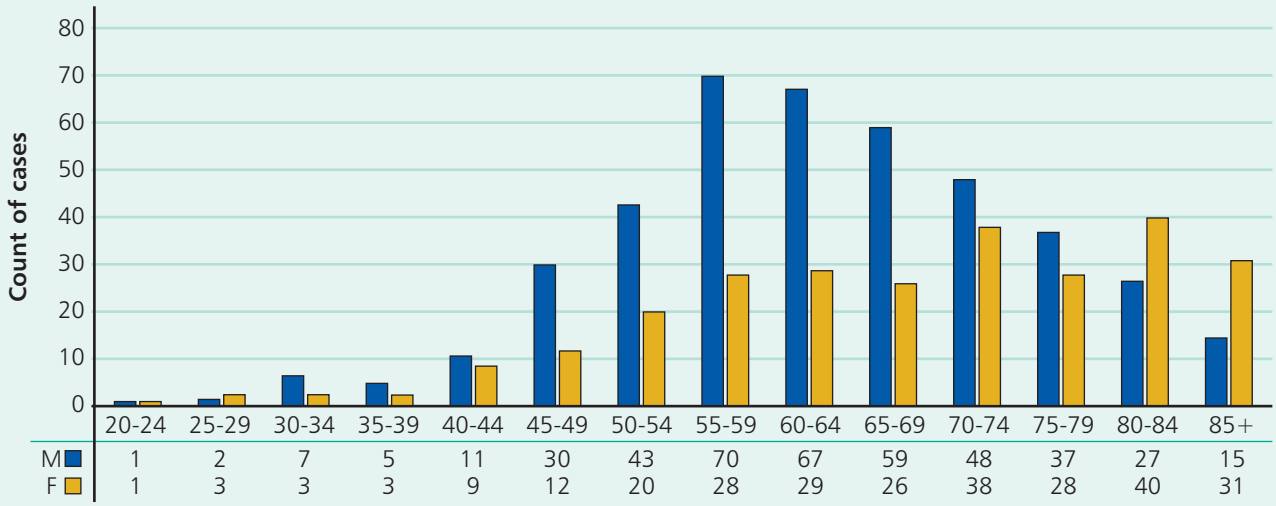


	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+
M	2	4	18	50	71	163	173	163	143	150	79	41
F	2	3	10	12	20	20	37	33	37	22	26	11

- Cumulative data from the inception of the audit shows similar distributions by age band supporting the findings above and confirming contribution from a homogenous population.

Oral Cavity

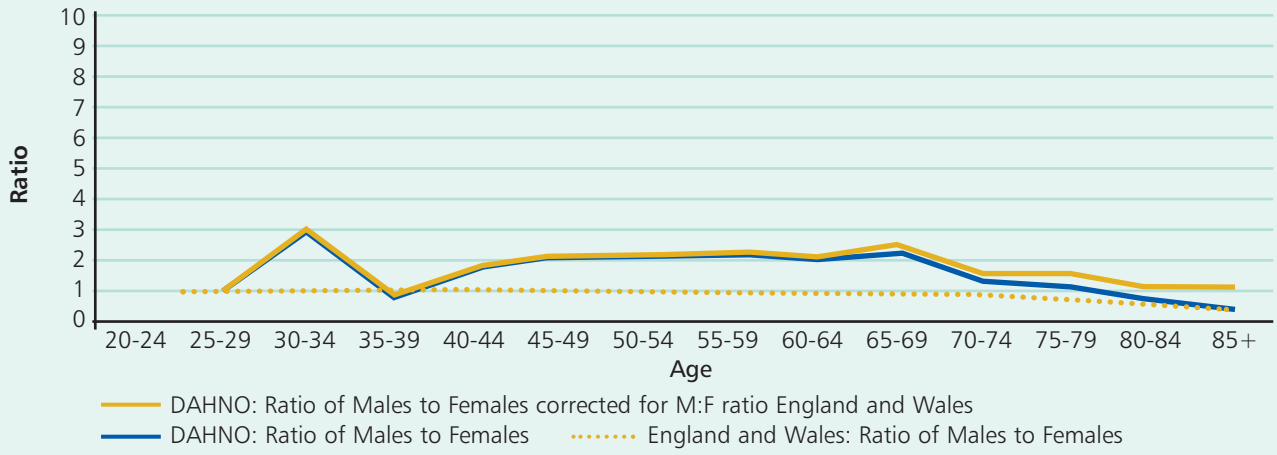
Figure 8.4.1.d: Oral Cavity Cancer; Registration counts by age and sex



2 cases had unrecorded gender, aged 72 and 84, 2 cases had unrecorded date of birth both males

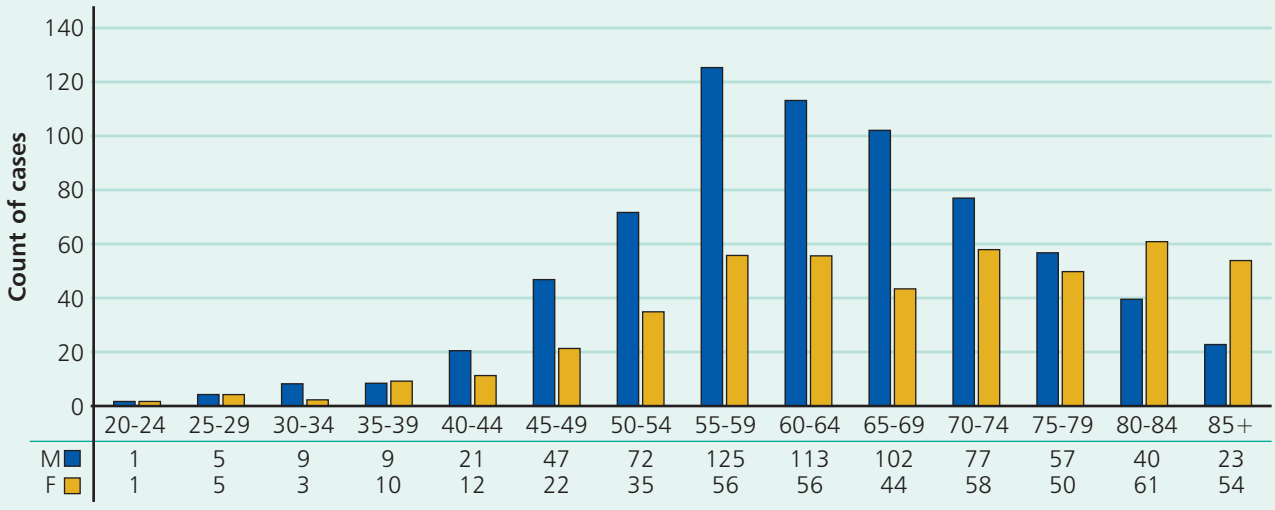
- 61 per cent of cases of oral cavity cancer were male.
- 13 per cent of patients were aged under 50 years.
- The median age for males was 63 years and 70 years for females.
- 13 per cent of male cases were under the age of 50.
- 17 per cent were aged over 75.
- 11 per cent of female cases were under the age of 50.
- 35 per cent were aged over 75.
- The apparent trend seen in last year's report of a second peak of registrations in elderly females is again seen in this year's data, and in the combined data from the audit's inception. However further analysis of this trend is discussed below.
- DAHNO registrations are broadly in line with the ONS which reports rates of oral cancer in men approximately double that in women at the age of 50, but approximately equal over the age of 80.
- The fact that more cancer cases have been recorded in older females than older males is accounted for by the greater life expectancy of females, and consequently there is a larger population over the age of 80 than of men.

Figure 8.4.1.e: Ratio of male to female registrations oral cavity cancer compared with ratio of males to females in England and Wales, January 2004 to October 2006



- The ratio of male to female oral cavity cancers exceeds the ratio of males to females in England and Wales by a factor of approximately 2 between the ages of 40 and 80. This suggests that the risk of oral cavity cancer in males is approximately double than in females between the ages of 40 and 80; beyond this age risk is approximately equal. Using National age-sex distribution in each age band a better comparison of true incidence can be made.

Figure 8.4.1.f: Oral Cavity; Cancer Registration Counts by age and sex, January 2004 to October 2006



	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75-79	80-84	85+
M	1	5	9	9	21	47	72	125	113	102	77	57	40	23
F	1	5	3	10	12	22	35	56	56	44	58	50	61	54

2 cases had unrecorded gender, aged 72 and 84; 2 cases had unrecorded date of birth both males

- Cumulative data from the inception of the audit shows similar distributions by age band supporting the findings above and confirming contribution from a homogenous population.

A number of recent publications have demonstrated an increasing incidence of oral squamous cell carcinoma (particularly of the tongue) occurring in younger patients (under 40 years). Two consecutive years data have failed to demonstrate this phenomenon. Registrations do not appear to confirm the trend of a rising occurrence in young people. However, not all cases have been registered in this time frame.

8.4.2 Distribution of stage

8.4.2.1 Larynx

8.4.2.1.1 Stage at diagnosis

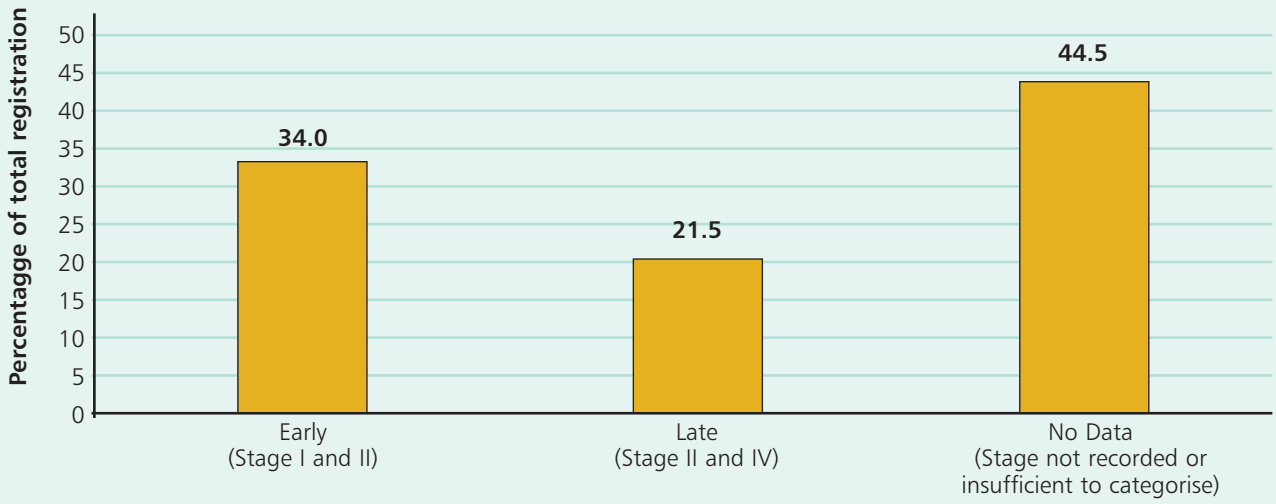
Figure 8.4.2.1.1.a: Larynx; Stage at diagnosis

Percentage of 745 recorded cases

	T category						
N Category	**T1**	**T2**	**T3**	**T4**	**TX**	**Not Recorded**	**Total**
N0	19.5	12.1	5.2	4.6	0.4	0.5	**42.3**
N+	0.4	2.0	3.2	5.1	0.1	0.1	**11.0**
NX	0.4		0.7	0.1	7.8		**9.0**
Not recorded	1.7	0.7	0.5	0.1		34.6	**37.7**
Total	**22**	**14.8**	**9.7**	**9.9**	**8.3**	**35.3**	**100**

- 64.7 per cent had T category recorded.
- 62.3 per cent had N category recorded.
- 62.6 per cent of cases had M category recorded, of which 0.7 per cent were M1, confirming the low propensity of laryngeal carcinomas of presenting with distant metastatic disease.

Figure 8.4.2.1.1.b: Larynx; Stage at diagnosis



- 55.5 per cent of laryngeal cancers have stage at diagnosis recorded.
- 44.5 per cent of laryngeal cancers have no staging recorded, or insufficient information to categorise stage. The figures do not show an improvement on the previous year which is disappointing.
- In laryngeal cancer, as previously found, early stage disease predominates.[16]

Recording cancer site and accurate stage is a key medical responsibility, with best practice suggesting that this should be clearly documented and captured at the MDT. Staging remains a key influence on outcome. It is important that this improves to achieve 100 per cent of cases staged in any high quality database collection, to allow valid comparisons to be made.

8.4.2.1.2 Comparison of stage at diagnosis and post-surgery staging

Of the 171 patients recorded as undergoing surgery, information on stage at diagnosis, with post surgical staging (i.e. based on resective pathology), was available for T category in 109 patients and N category in 104 patients.

Figure 8.4.2.1.2.a: Comparison of stage at diagnosis and post-surgery staging

		Diagnosis					
	T	**T1**	**T2**	**T3**	**T4**	**TX**	**Total**
Post-surgery	T1	33	1				34
	T2		11		1		12
	T3		1	17			18
	T4		1	6	26	1	34
	TX	2	2			7	11
	Total	**35**	**16**	**23**	**27**	**8**	**109**

- In T category, 8 patients were upstaged following surgery, and 3 downstaged.

Figure 8.4.2.1.2.b: Comparison of stage at diagnosis and post-surgery staging

		Diagnosis					
	N	**N0**	**N1**	**N2**	**N3**	**NX**	**Total**
Post-surgery	N0	61		4			65
	N1	1	6				7
	N2	1		12		2	15
	N3				4		4
	NX	5				8	13
	Total	**68**	**6**	**16**	**4**	**10**	**104**

- 2 patients were upstaged and 4 patients were downstaged, which shows a level of correlation expected rather than the previous absence of any change in N category. The sample size however is too small and incomplete at this stage to draw any definitive conclusions.

8.4.2.1.3 Summary of recorded stage certainty

Percentage of cases with recorded T N M category (423 T category recorded; 397 N category recorded; 329 M category recorded).

Figure 8.4.2.1.3.a: Summary of recorded stage certainty

	Stage Certainty				
Stage Category	**C1**	**C2**	**C3**	**C4**	**Not Recorded**
Cases with recorded T	15.4	20.3	27.0	1.9	35.5
Cases with recorded N	16.4	21.7	26.2	2.0	33.8
Cases with recorded M	17.6	22.8	28.3	2.4	28.9

- 64.5 per cent had T stage certainty factor recorded, 66.2 per cent had N stage certainty factor recorded and 71.1 per cent had M stage certainty factor recorded.
- There has been a significant improvement in recording this item, during the audit period.
- At key points in the patient pathway, staging is a defining parameter which allows for more interpretation of outcome, which facilitates grouping a description of disease extent in a uniform manner, to allow valid comparison.

Figure 8.4.2.1.3.b: Summary of recorded stage certainty

Certainty factor

C1	Evidence from standard diagnostic means *(e.g. inspection, palpation, and standard radiography, intraluminal endoscopy for tumours of certain organs).*
C2	Evidence obtained by special diagnostic means *(e.g. radiographic imaging in special projections, tomography, computerised tomography (CT), ultrasonography, lymphography, angiography, scintigraphy, magnetic resonance imaging (MRI), endoscopy, biopsy and cytology).*
C3	Evidence from surgical exploration, including biopsy and cytology.
C4	Evidence of the extent of disease following definitive surgery and pathological examination of the resected specimen.
C5	Evidence from autopsy.

Stage certainty is a relatively new concept to clinicians and links to the category (TNM) recorded, the means by which this was established and the degree of confidence associated with the diagnosis.[10]

- Over two-thirds of laryngeal cases had certainty factor completed, which is good progress. This may represent benefits from the prominence given to training in the DAHNO Workshops. However, it would be expected that the numbers with C4 should be greater based on the number of resective procedures performed.

For those cases undergoing surgical management it is important that resective pathology is accurately recorded to allow true stage comparison. Surgical teams should develop responsibilities in this key area.

8.4.2.2 Oral cavity

8.4.2.2.1 Stage at diagnosis

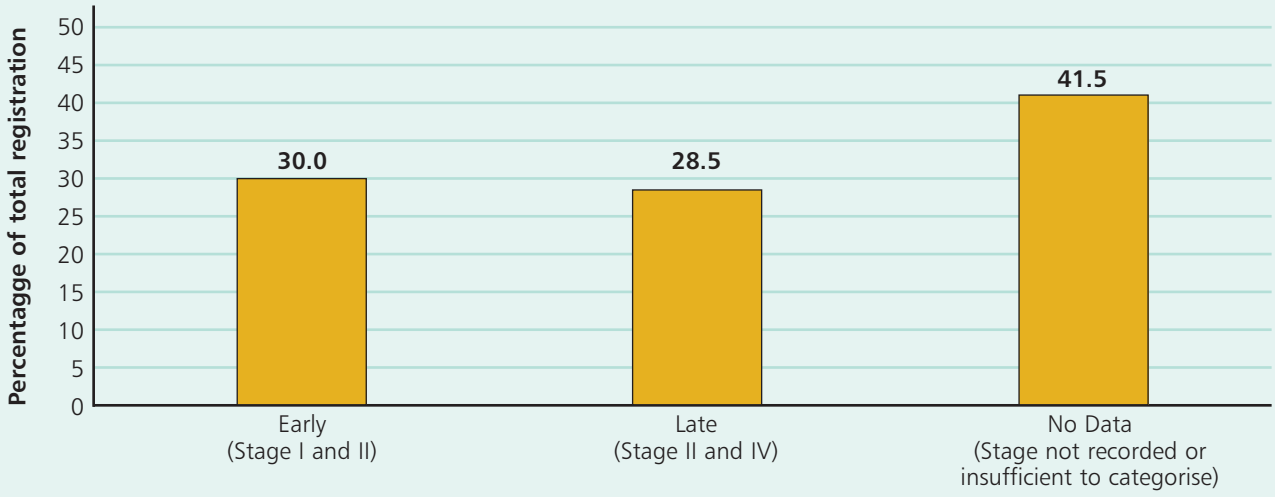
Figure 8.4.2.2.1.a: Oral Cavity; Stage at diagnosis

Percentage of 698 recorded cases

	T category						
N Category	**T1**	**T2**	**T3**	**T4**	**TX**	**Not Recorded**	**Total**
N0	17.6	9.3	2.1	8.0		0.4	**37.4**
N+	2.3	4.9	3.3	8.5		0.1	**19.1**
NX	1.0	0.3		0.3	4.1		**5.7**
Not recorded	1.4	0.6		0.6		35.3	**37.8**
Total	**22.3**	**15**	**5.4**	**17.4**	**4.1**	**35.8**	**100**

- 64.2 per cent had T category recorded.
- 62.2 per cent had N category recorded.
- 61.7 per cent of cases had M category recorded, of which 0.7 per cent were M1, confirming the low propensity of laryngeal carcinomas of presenting with distant metastatic disease.

Figure 8.4.2.2.1.b: Oral Cavity; Stage at diagnosis



58.5 per cent of oral cavity cancers have stage at diagnosis recorded.

41.5 per cent of oral cancers have no staging recorded, or insufficient information to categorise stage. The figures do not show an improvement on the previous year which is disappointing.

Recording cancer site and accurate stage is a key medical responsibility, with best practice suggesting that this should be clearly documented and captured at the MDT. Staging remains a key influence on outcome. It is important that this improves to achieve 100 per cent of cases staged in any high quality database collection, to allow valid comparisons to be made.

The previously noted dominance of late stage cancer is not evident in this year's data. However no firm conclusion can be drawn due to the high level of no stage recorded or insufficient TNM to categorise.

8.4.2.2.2 Comparison of stage at diagnosis and post-surgery staging

Of the 362 patients recorded as undergoing surgery, information on stage at diagnosis, with post surgical staging (i.e. based on resective pathology), was available for T category in 237 patients and N category in 227 patients.

- 65 per cent of patients undergoing surgery had post resective surgery staging details recorded.

Figure 8.4.2.2.2.a: Comparison of stage at diagnosis and post-surgery staging

		Diagnosis					
	T	**T1**	**T2**	**T3**	**T4**	**TX**	**Total**
Post-surgery	T1	100	7		3	1	111
	T2	2	56	3	1	1	63
	T3		1	15	1		17
	T4	1	2	2	40		45
	TX					1	1
	Total	**103**	**66**	**20**	**45**	**3**	**237**

- In T category, 8 patients were upstaged following surgery and 15 were downstaged (10 per cent change in stage).

Figure 8.4.2.2.2.b: Comparison of stage at diagnosis and post-surgery staging

		Diagnosis					
	N	**N0**	**N1**	**N2**	**N3**	**NX**	**Total**
Post-surgery	N0	141	8	2		2	153
	N1	4	22				26
	N2	5	3	29		1	38
	N3				2		2
	NX	2		1		5	8
	Total	**152**	**33**	**32**	**2**	**8**	**227**

- 12 patients were upstaged and 10 patients were downstaged (10 per cent change in stage). This is consistent with last year's data. The sample size however is too small and incomplete at this stage to draw any definitive conclusions.
- The number of patients upstaged following surgery seems low compared to published estimates of occult metastasis in squamous cell carcinoma of the oral cavity. Given the predominance of cancer of the tongue in the cases submitted it might be expected that higher percentage of upstaging would be seen.

8.4.2.2.3 Summary of recorded stage certainty

Percentages of cases with recorded T N M (421 T category recorded; 394 N category recorded and 318 M category recorded).

Figure 8.4.2.2.3.a: Summary of recorded stage certainty

	Stage Certainty					
Stage Category	**C1**	**C2**	**C3**	**C4**	**Not Recorded**	**Total**
Cases with recorded T	11.4	20.2	32.3	7.6	28.5	100
Cases with recorded N	16.8	43.7	8.1	4.8	26.6	100
Cases with recorded M	43.7	27.0	6.0	0.6	22.6	100

- 71.5 per cent had T stage certainty factor recorded, 73.4 per cent had N stage certainty factor recorded and 77.4 per cent had M stage certainty factor recorded.
- This is a significant improvement this year in the recording of this item.
- At key points in the patient pathway, staging is a defining parameter which allows for more interpretation of outcome, which facilitates grouping a description of disease extent in a uniform manner, to allow valid comparison.
- Nearly three-quarters of oral cases had certainty factor completed, which represents good progress. This may represent benefits from the prominence given to training in the DAHNO Workshops. However, it would be expected that the numbers with C4 should be greater based on the number of resective procedures performed.

For those cases undergoing surgical management it is important that resective pathological staging including certainty factor is accurately recorded to allow true stage comparison. Surgical teams should take responsibilities in this key area.

Figure 8.4.2.2.3.b: Summary of recorded stage certainty

Certainty factor

C1 Evidence from standard diagnostic means (e.g. inspection, palpation, and standard radiography, intraluminal endoscopy for tumours of certain organs).

C2 Evidence obtained by special diagnostic means (e.g. radiographic imaging in special projections, tomography, computerised tomography (CT), ultrasonography, lymphography, angiography, scintigraphy, magnetic resonance imaging (MRI), endoscopy, biopsy and cytology).

C3 Evidence from surgical exploration, including biopsy and cytology.

C4 Evidence of the extent of disease following definitive surgery and pathological examination of the resected specimen.

C5 Evidence from autopsy.

8.4.3 Distribution of performance status at point of treatment decision

Larynx

Figure 8.4.3.a: Larynx; Distribution of performance status at point of treatment decision

Performance status	Percentage of 292 recorded values
0. Able to carry out all normal activity without restriction	46.6
1. Restricted in physically strenuous activity	17.1
2. Able to walk and capable of all self care but unable to carry out any work	11.0
3. Capable of only limited self care	3.4
4. Completely disabled	1.4
5. Not recorded	20.5
Total	**100**

Oral cavity

Figure 8.4.3.b: Oral Cavity; Distribution of performance status at point of treatment decision

Performance status	Percentage of 288 recorded values
0. Able to carry out all normal activity without restriction	55.6
1. Restricted in physically strenuous activity	18.1
2. Able to walk and capable of all self care but unable to carry out any work	10.1
3. Capable of only limited self care	5.2
4. Completely disabled	0.0
5. Not recorded	11.1
Total	**100**

- 1,159 patients had at least one careplan. (A careplan represents the point in the patient pathway where a plan of treatment is proposed and thus an appropriate point to assess and record a patient's fitness).
- 580 patients had performance status recorded, which is 40 per cent of the total registrations. This equates to 50 per cent of patients with a recorded careplan.
- To facilitate risk adjustment further training on performance status and completeness is required. The figures for the first two annual reports suggest that the majority of patients have a normal performance status and there appears to be equivalence between the oral cavity and laryngeal groups.

8.4.4 Presence or absence of significant comorbidity at index point of diagnosis (ACE-27)

8.4.4.1 Summary of recorded comorbidity

Larynx

- 582 patients had at least one careplan.
- 144 patients had comorbidity index recorded. This is 25 per cent of patients with a recorded careplan, which is 20 per cent of total registrations.

Figure 8.4.4.1.a: Larynx; Summary of recorded comorbidity

Grade	Percentage of 144 recorded values
Grade 0 - No comorbidity	50.7
Grade 1 - Mild decompensation	22.9
Grade 2 - Moderate decompensation	17.4
Grade 3 - Severe decompensation	9.0
Total	**100**

Oral Cavity

- 577 patients had at least one careplan.
- 157 patients had comorbidity index recorded. This is 27 per cent of patients with a recorded careplan, which is 23 per cent of total registrations.

Figure 8.4.4.1.b: Oral Cavity; Summary of recorded comorbidity

Co-morbidity index	Percentage of 157 recorded values
Grade 0 - No comorbidity	49.7
Grade 1 - Mild decompensation	22.9
Grade 2 - Moderate decompensation	19.8
Grade 3 - Severe decompensation	7.6
Total	**100**

Co-morbidity has been shown to have an important impact in assessing risk and to be an important predictor of outcome. Further effort will be put into training workshops to encourage completeness. All MDT's are encouraged to collect comorbidity data.

- The figures in this year's report do not show the previously noted greater frequency of moderate and severe decompensation. The figures are closer to those of an previous UK population of larynx only cancer patients studied.
- The figures for comorbidity suggest that 50 per cent of the total population (larynx and oral cavity) patients had no comorbidity. This appears to tally with the normal performance status in the previous output (8.4.3)

The influence of factors such as comorbidity and performance status can have a significant effect upon treatment outcomes. Therefore all MDT's are to be encouraged to collect these data set items.

8.4.5 Distribution of diagnosis, treatment and outcome by socio-economic super-group, derived from the postcode in England

The Index of Multiple Deprivation 2004 (IMD 2004) was used as a measure of socio-economic deprivation and is applicable in England.

The lower the index score, the greater the level of deprivation, thus the first quintile represents those who are most deprived.

Thirty registrations did not have a valid postcode and, therefore, a deprivation score could not be calculated.

To investigate any bias that may be caused by the partial coverage of the DAHNO audit, the registrations have been totalled by the average deprivation of their PCT of residence. A deprivation score is attributed to (English) PCTs according to the population weighted mean score of the Super Output Areas that make up that PCT. PCTs were then ranked at categorised into quintiles. The total registrations by PCT deprivation are below, and show no particular bias.

Figure 8.4.5.a: Deprivation quintile of PCT

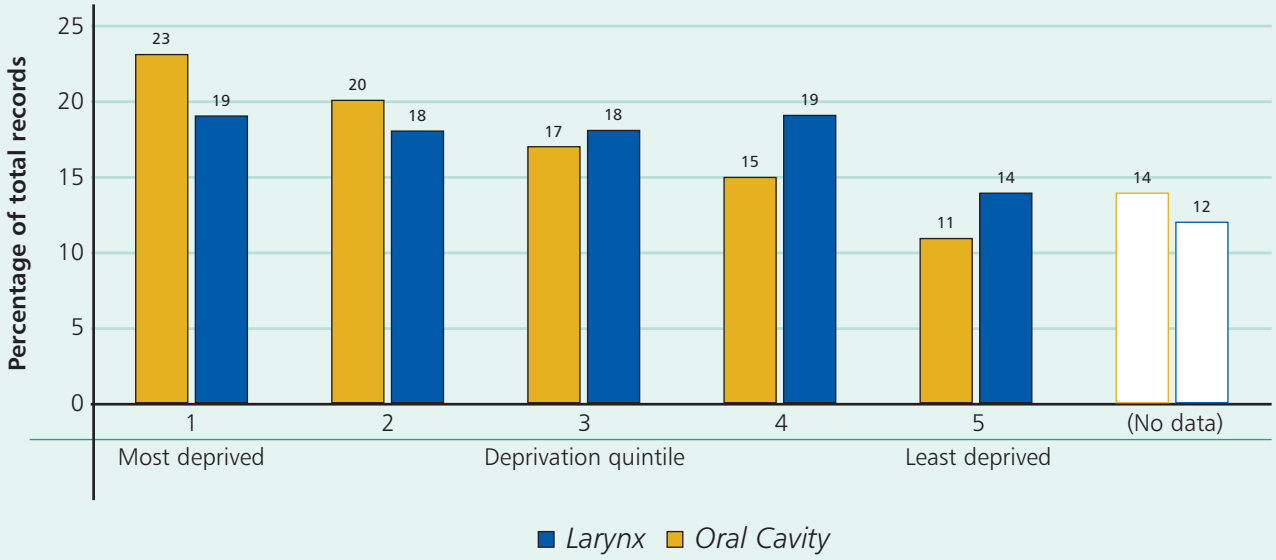
Deprivation quintile of PCT	Total
Least deprived	191
4	206
3	251
2	339
Most Deprived	240
Blank	216
Total	**1,443**

Figure 8.4.5.b: Deprivation quintile of PCT- Percentage of PCTs with some cases in DAHNO

Deprivation quintile of PCT	Percentage of PCTs with some cases in DAHNO
Least Deprived	70
4	70
3	72
2	70
Most Deprived	57

8.4.5.1 Summary of registrations by deprivation in England

Figure 8.4.5.1.a: Summary of registrations by deprivation in England



- The distribution of cases is more even across the deprivation quintiles for both larynx and oral cavity, though a greater number of larynx registrations reside in areas of relative deprivation (quintiles 1 and 2).

8.4.5.2 Deprivation and stage in England

Figure 8.4.5.2.a: Deprivation and stage in England

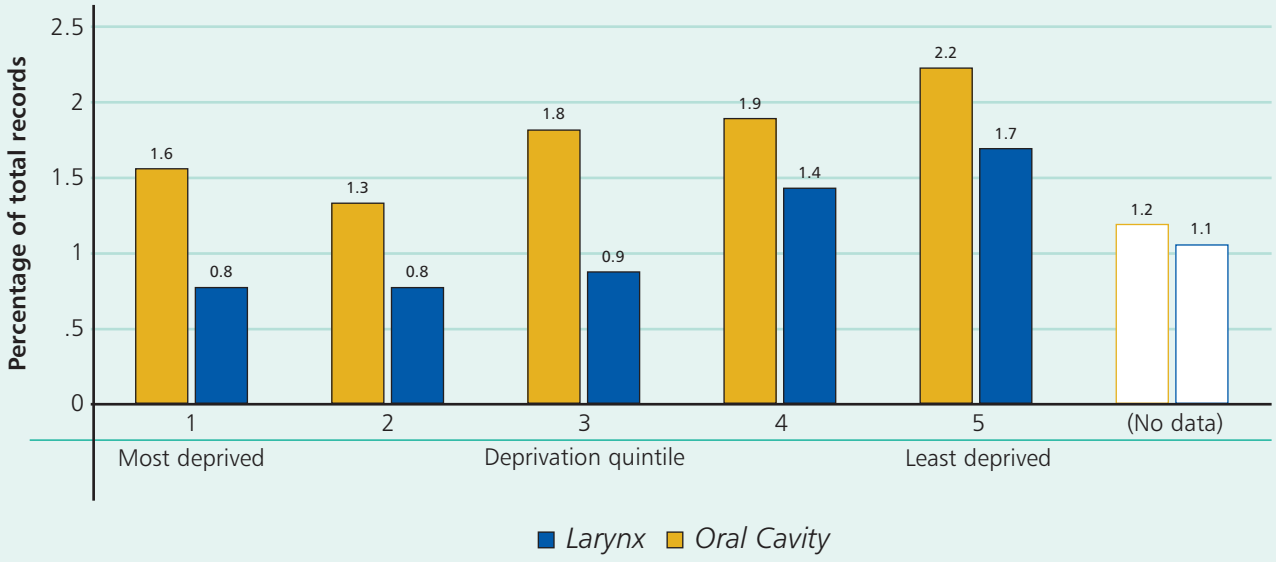
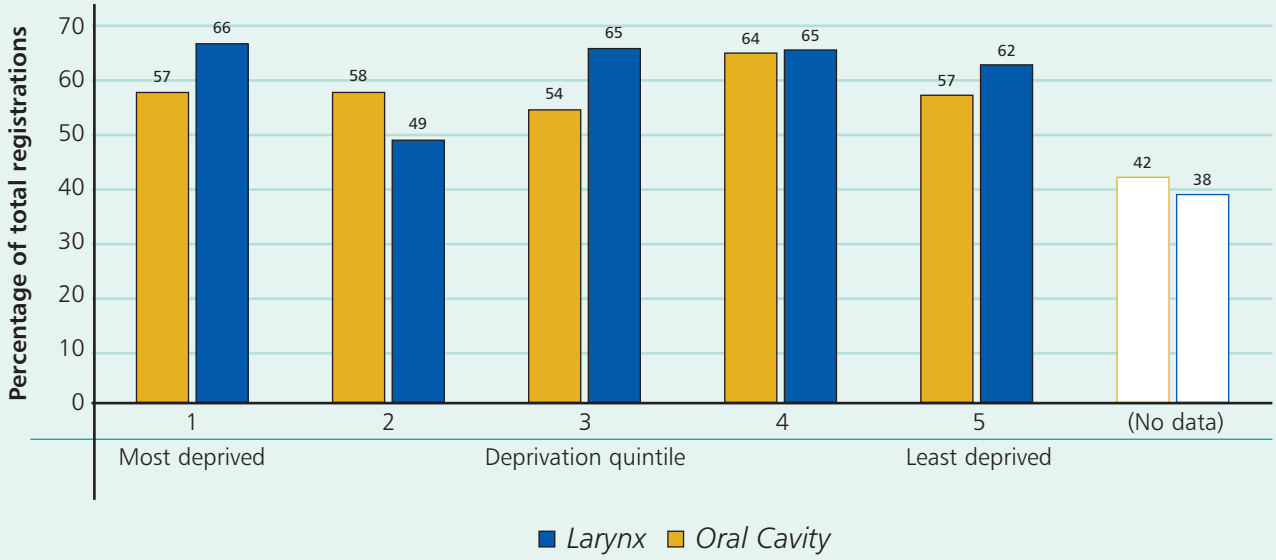


Figure 8.4.5.2.b: Proportion of registrations with sufficient stage data to categorise as early or late

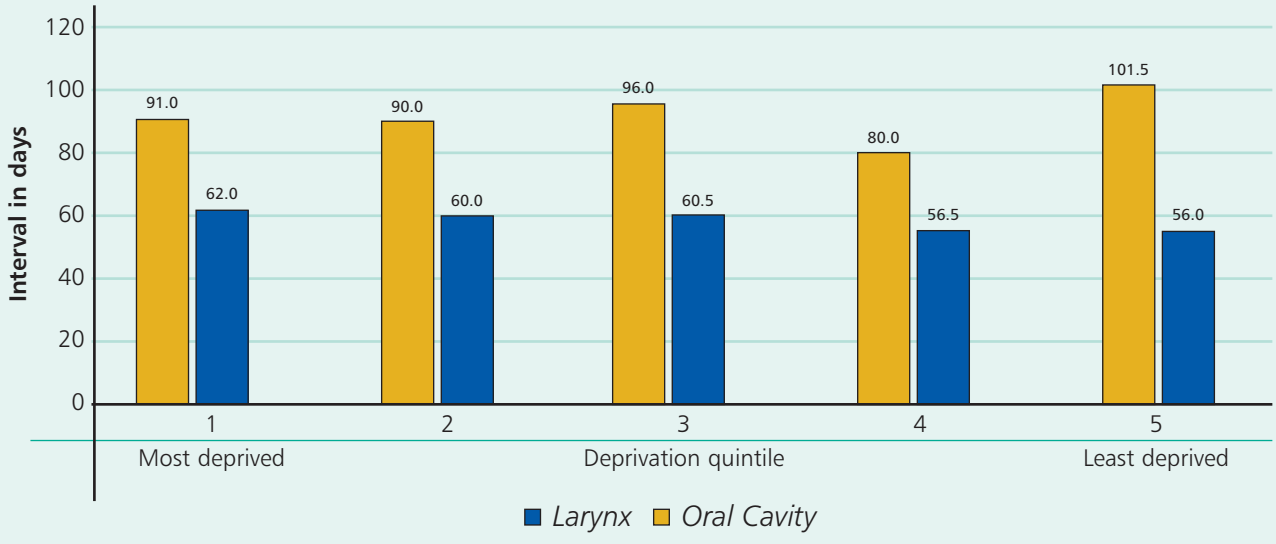


- Figure 8.4.5.2.b demonstrates the percentage of registrants who have staging information recorded for each deprivation quintile. The similar proportions across the quintiles show that the distribution in Figure 8.4.5.2.a is not biased by incomplete staging.

Limited conclusions can be drawn from the above chart regarding any relationship between stage at diagnosis and deprivation. There remains an indication that at diagnosis late stage cancer is more likely in the most deprived, while amongst the least deprived early stage cancer is more common. This year's report has a higher stage completion and the trend persists. Better data submissions in the future will enable more in depth analysis. This is an area of significant interest and will be examined more closely in future reports.

8.4.5.3 Deprivation and interval from onset of first symptom to referral in England

Figure 8.4.5.3.a: Larynx and Oral Cavity- Interval from first symptom to referral by socio-economic deprivation in England

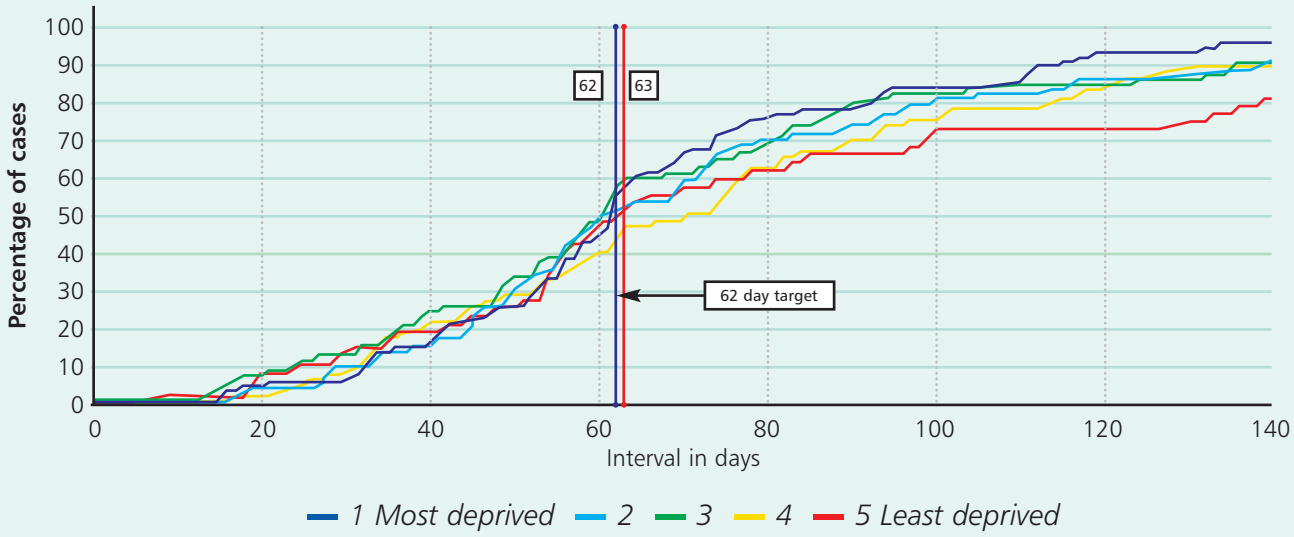


- It has previously proposed that deprivation has a bearing on delayed presentation and delayed onward referral.

No clear relationship is shown between the interval from onset of first symptom to referral and deprivation for either larynx or oral cavity cancer.

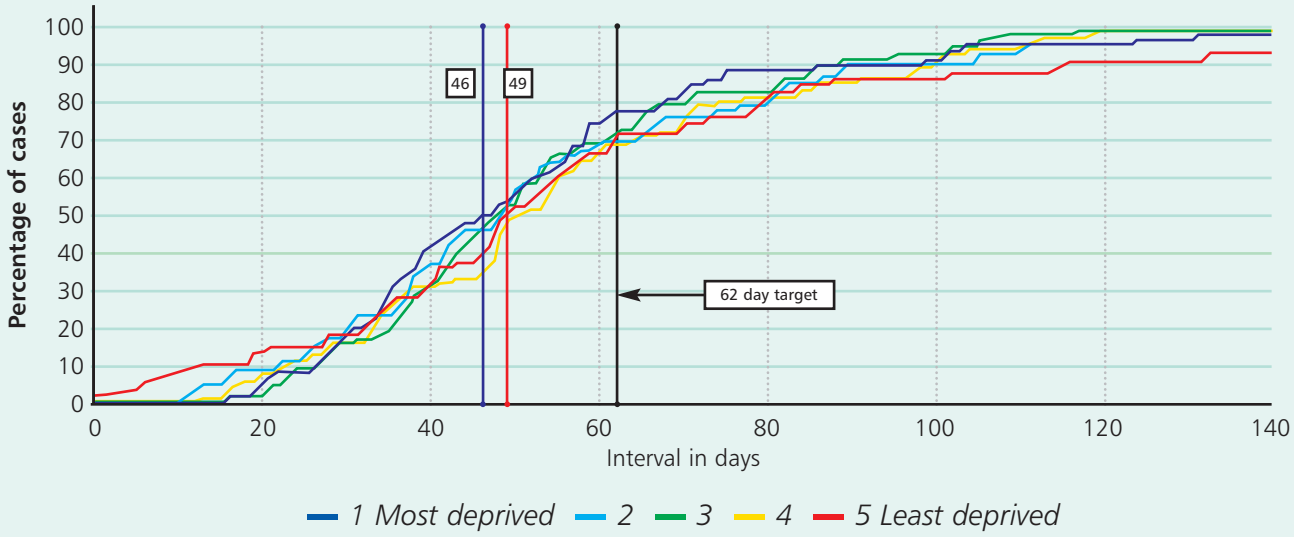
8.4.5.4 Deprivation and interval from referral to treatment in England

Figure 8.4.5.4.a: Larynx - Interval from referral to first recorded treatment by socio-economic deprivation in England



- The interval from referral to first recorded treatment by deprivation quintile shows near identical median values between the most deprived and least. This is in sharp contrast to an over 30 day difference between the most deprived and least deprived evident in the first Annual Report.

Figure 8.4.5.4.b: Oral Cavity - Interval from referral to first recorded treatment by socio-economic deprivation in England



- The interval from referral to first recorded treatment by deprivation quintile shows near identical median values. This is in sharp contrast to a 20 day difference between the most deprived and least deprived evident in the first Annual Report.

8.5 The patient journey - diagnostic and staging process, waiting intervals

8.5.1 Source of referral to specialist team in England

8.5.1.1 Larynx

Figure 8.5.1.1.a: Larynx; Source of referral to specialist team in England

Primary referral source	2ww from GP or dentist	Other	Not recorded	Total
GP	274	184	2	460
GDP / CDs		1		1
Emergency / A&E		25		25
Consultant referral	2	101	1	104
Self / Other		36	7	43
Unknown	6	14	4	24
Total	**282**	**361**	**14**	**657**

The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.

- There is a ratio of 1.49:1 in referral via the two week wait urgent referrals pathway compared to other referral priorities, in referrals from general practitioners in those with diagnosed cancer. However, the audit has not sampled the total number of referrals from which these derived.
- This compares in 2005 to 1.7:1 suggesting that less patients with cancer are being referred via the two week rule.

8.5.1.2 Oral cavity

Figure 8.5.1.1.b: Oral Cavity; Source of referral to specialist team in England

Primary referral source	2ww from GP or dentist	Other	Not recorded	Total
GP	217	107	2	326
GDP / CDS	25	83	1	109
Emergency / A&E		16	1	17
Consultant referral	2	100	2	104
Self / Other	1	46	4	51
Unknown	4	9	6	19
Total	**249**	**361**	**16**	**626**

The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.

- There is a ratio of 2.02:1 in referral via the two week wait urgent referral pathway compared to other referral priorities, in referrals from general medical practitioners in those with diagnosed cancer, and a ratio of 0.30:1 for those referred under the two week wait from general dental practitioners (GDP) / Community Dental Services (CDS). General dental practitioners have not been involved in the urgent cancer referral process since its launch. Targeted publications and their future involvement in the two week referral pathway may improve this. The audit, however, has not sampled the total number of referrals from which these derived.
- This compares in 2005 to 2.5:1 suggesting that less patients with cancer are being referred via the two week rule from general practitioners.
- It would appear that only a small proportion of two week wait referral are coming thorough the dental practitioner route. This may reflect lack of awareness of the two week rule referral process by GDP's or reflects access difficulties to primary care dental services.
- Overall there has been a significant increase in the recording of referral data and contributors should be commended.

8.5.2 Summary as percentage of cases with both 'primary referral priority' and 'primary referral source' completed in England

8.5.2.1 Larynx

Figure 8.5.2.1.a: Larynx; Summary as percentage of cases with both 'primary referral priority' and 'primary referral source' completed

Percentage of 623 cases

Primary referral source	2ww from GP or dentist	Other Priority	Total
GP	44.0	29.5	73.5
GDP / CDS		0.2	0.2
Emergency / A&E		4.0	4.0
Consultant referral	0.3	16.2	16.5
Self / Other		5.8	5.8
Total	**44.3**	**55.7**	**100**

The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.

- 73.5 per cent of those diagnosed with laryngeal cancer are referred by their general practitioner, whilst of the remaining 26.5 per cent, 16.5 per cent are referred from another consultant.

8.5.2.2 Oral cavity

Figure 8.5.2.2.a: Oral Cavity; Summary as percentage of cases with both 'primary referral priority' and 'primary referral source' completed

Percentage of 597 cases

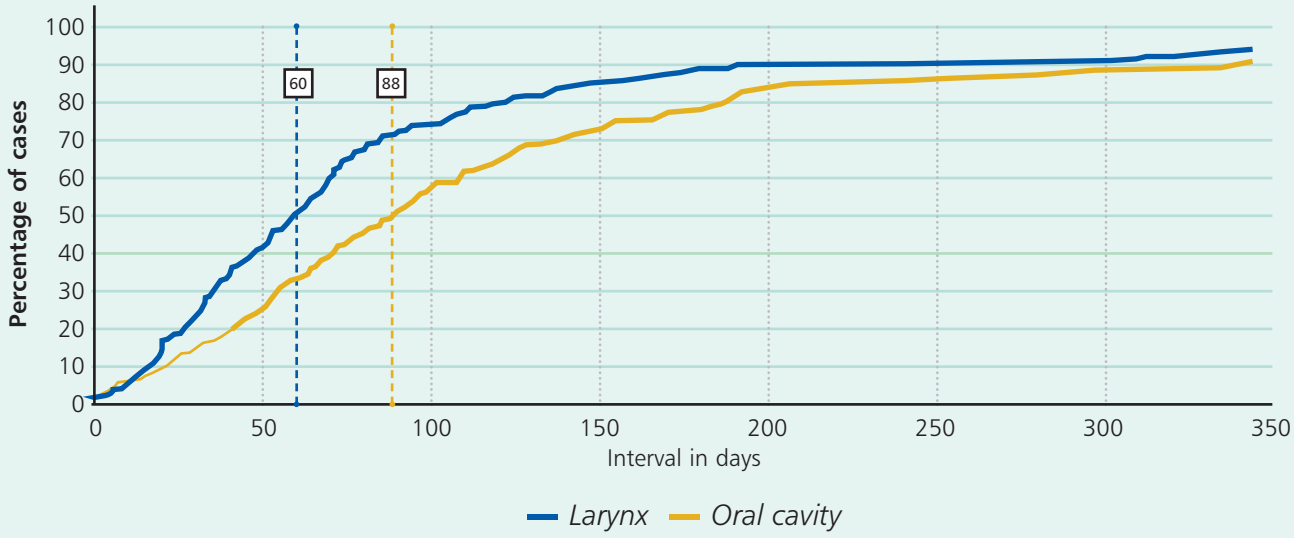
Primary referral source	2ww from GP or dentist	Other Priority	Total
GP	36.3	17.9	54.3
GDP / CDS	4.2	13.9	18.1
Emergency / A&E		2.7	2.7
Consultant referral	0.3	16.8	17.1
Self / Other	0.2	7.7	7.9
Total	**41.0**	**59.0**	**100**

The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.

- 54.3 per cent of those diagnosed with oral cavity cancer are referred by their general practitioner while of the remaining 45.7 per cent, 17 per cent are referred from another consultant and 18 per cent from a general dental practitioner or the Community Dental Service. This demonstrates the importance of general dental services in screening for oral cavity cancer.

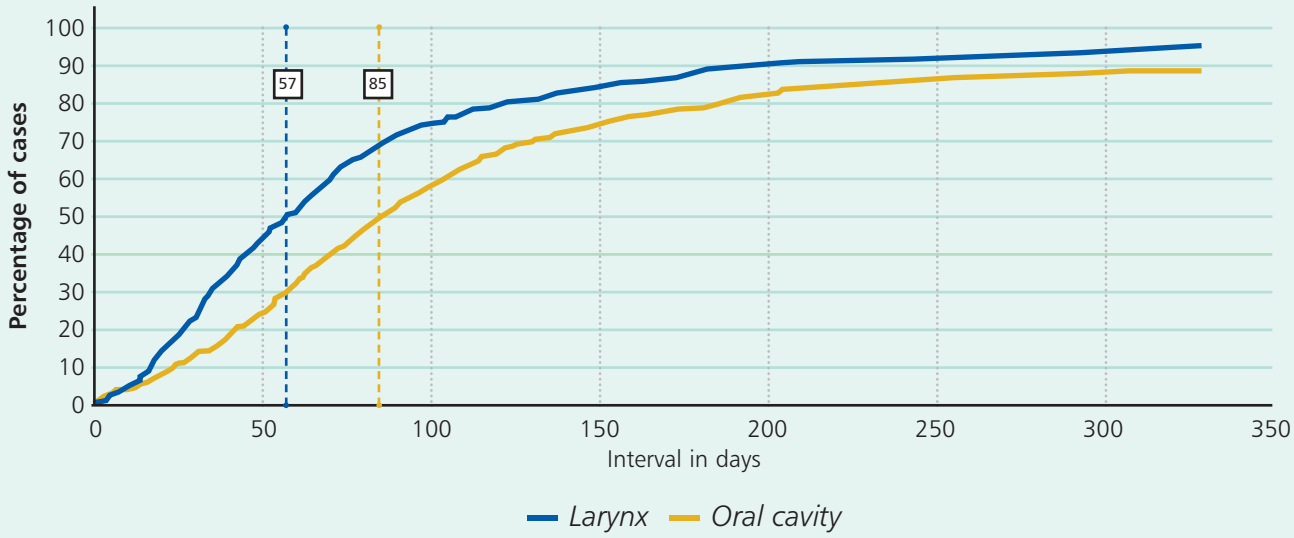
8.5.3 Interval from first symptom to referral to specialist team

Figure 8.5.3.a: Interval from first symptom to referral to specialist team



- Patient recall of the onset of their first symptom to their point of referral is a crude indicator of patient awareness. The figures presented suggest earlier presentation of oral cavity cancer (median interval 60 days) compared to laryngeal cancer (median interval 88 days). This shows a similar difference to last year's Annual Report suggesting a trend and this may be because within the oral cavity, cancers are more visible.

Figure 8.5.3.b: Interval first symptoms to referral, January 2004 to October 2004

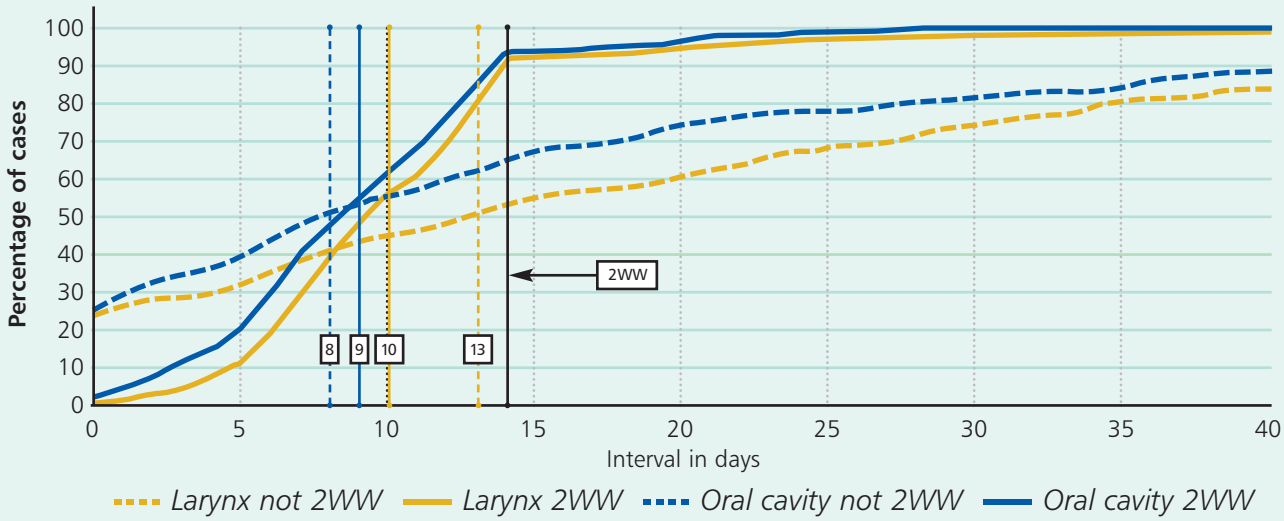


- The second chart shows data from the inception of the audit from 1,194 patients. The cumulative findings confirm a consistency in the reporting of median times from first symptom to referral for both larynx and oral cavity cancer.
- The significance of delay in outcome and stage at presentation remains controversial.
- Increasing patient and practitioner awareness of suspicious symptoms should yield an early diagnosis, particularly in larynx cancer.

Practitioners should be encouraged to familiarise themselves with and utilise national referral guidelines. National referral guidelines (Referral Guidelines for Suspected Cancers) can be found at: www.dh.gov.uk/assetRoot/04/01/44/21/04014421.pdf.

8.5.4 Interval from referral to first appointment in England

Figure 8.5.4.a: Interval from referral to first appointment in England

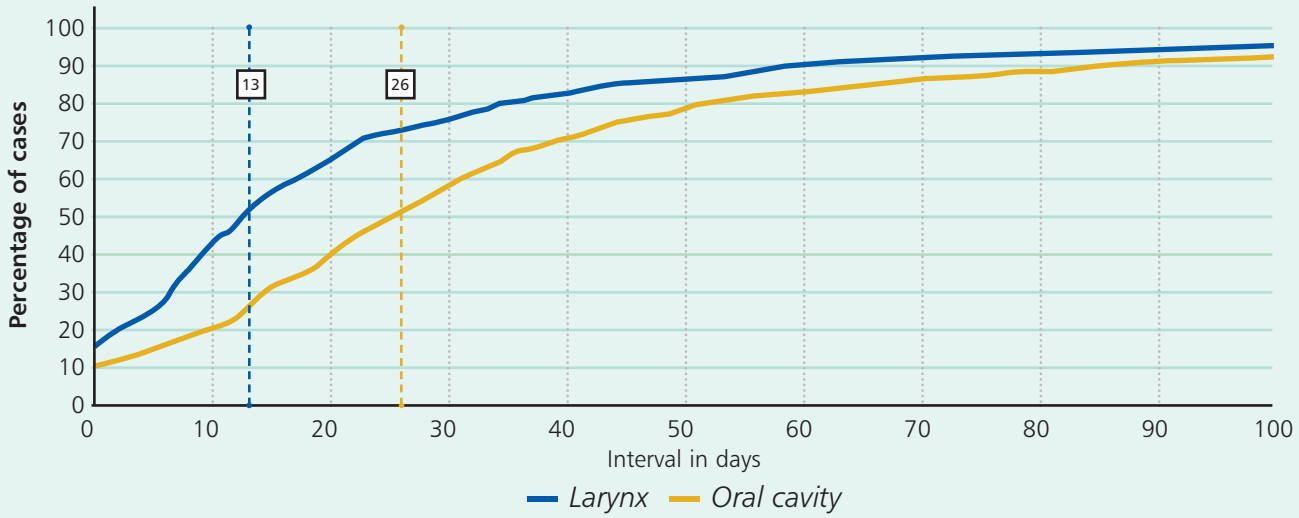


The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.

- The figure shows that for non two week wait referrals, 20 per cent have an interval from referral to first appointment of 0 days. This reflects self referrals, referrals to an Accident and Emergency Service and those seen on the day of phone or fax request.
- The two week wait rule for referral to first appointment was introduced in England in December 2000.[47] This is designed to speed up the patient's entry into the cancer care pathway. The median for both larynx and oral cavity two week wait and other referrals is comfortably within the standard, showing that patients with suspicious symptoms independent of route of referral are seen promptly. Again, however 20 per cent of other referrals in the sample are waiting over one month for their first appointment.
- With the implementation of National referral guidelines in England, (Guidance on Cancer Services - Improving Outcomes in Head and Neck Cancers and Referral Guidelines for Suspected Cancers)[19], it would be expected that an ever increasing proportion of patients will be referred via the two week wait pathway but this is not borne in this second period of data collection. The introduction of Choose and Book places upon the referrer the responsibility of requesting urgent priority for symptoms not falling into the two week wait criteria rather than a reliance upon triage.

8.5.5 Interval from referral to diagnosis in England and Wales

Figure 8.5.5.a: Interval from referral to diagnosis in England and Wales



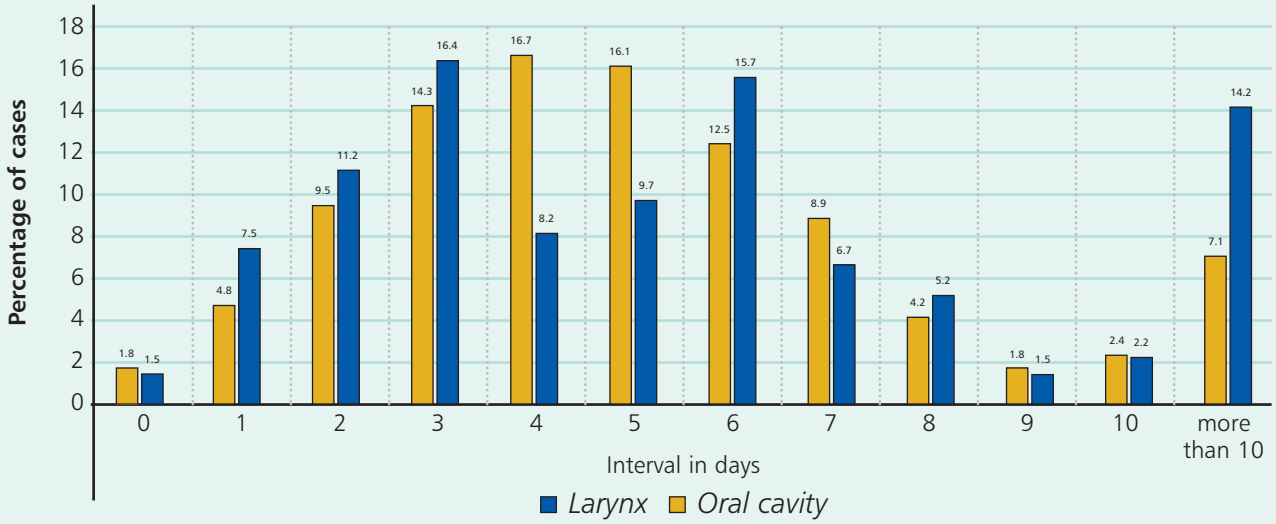
The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.

- The apparent more rapid diagnosis of oral cavity cancers may be explained by the fact that many of these diagnoses can be achieved via local anaesthetic out-patient biopsy, whereas for laryngeal cancer the requirement for general anaesthesia may induce additional delays. There have been small decreases for both larynx and oral cavity cancers in the time taken from referral to diagnosis in this period of data collection.
- In both larynx and oral cavity cancer, patients may present initially with precancerous lesions that are carefully followed up over extended periods. This can, therefore, mean that their ultimate diagnosis of cancer from referral may not occur until a significant time has elapsed. This is likely to explain why the graph shows that only 90 per cent of patients reach a diagnosis by 100 days and then plateaux.

8.5.5.1 Time from biopsy to reporting

This item is reported for the first time and represents the time from the biopsy being taken to its reporting.

Figure 8.5.5.1.a: Time from biopsy



The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.

- The median time from biopsy to its reporting is 5 days for both larynx and oral cavity.
- It is noted that 14 per cent of oral cavity cases reported have an interval greater than 10 days. This may reflect obtaining a specialist oral pathology opinion.

8.5.6 The multi-disciplinary team (MDT) and its functions

Figure 8.5.6.a: The multi-disciplinary team (MDT) and its functions

Discussed	Larynx	Oral Cavity	All
Yes	67.5	75.9	71.6
No	5.0	2.6	3.8
Not recorded	27.5	21.5	24.6

Note: Although this table reflects the number of patients discussed at MDT and this report makes reference to the MDT meeting, we refer to the standard definition of MDT from IOG. The data collected for the head and neck cancer audit does not indicate the understanding of what constitutes MDT.

- Overall 71 per cent of patients were confirmed as having been discussed at an MDT meeting. The expected standard (proposed in the SWAHN audit[30] 1997- 1999) suggested this should reach 100 per cent.
- It is a standard in the Improving Outcomes Guidance that all patients are discussed in an MDT[19].
- These results show that there has been a significant decrease in the number of patients whose management has been planned outside of an MDT. This is to be welcomed.
- However the absence of data in 27 per cent of larynx cancer and 21 per cent of oral cavity cancer is of concern as this may reflect a non ideal pathway with more treatment decisions being made outside of MDTs.
- The MDT is a key point of registration of a cancer diagnosis.

Patient expectations are that all care discussions are being made at a MDT, and head and neck cancer teams need to provide assurance around this important aspect of care delivery.

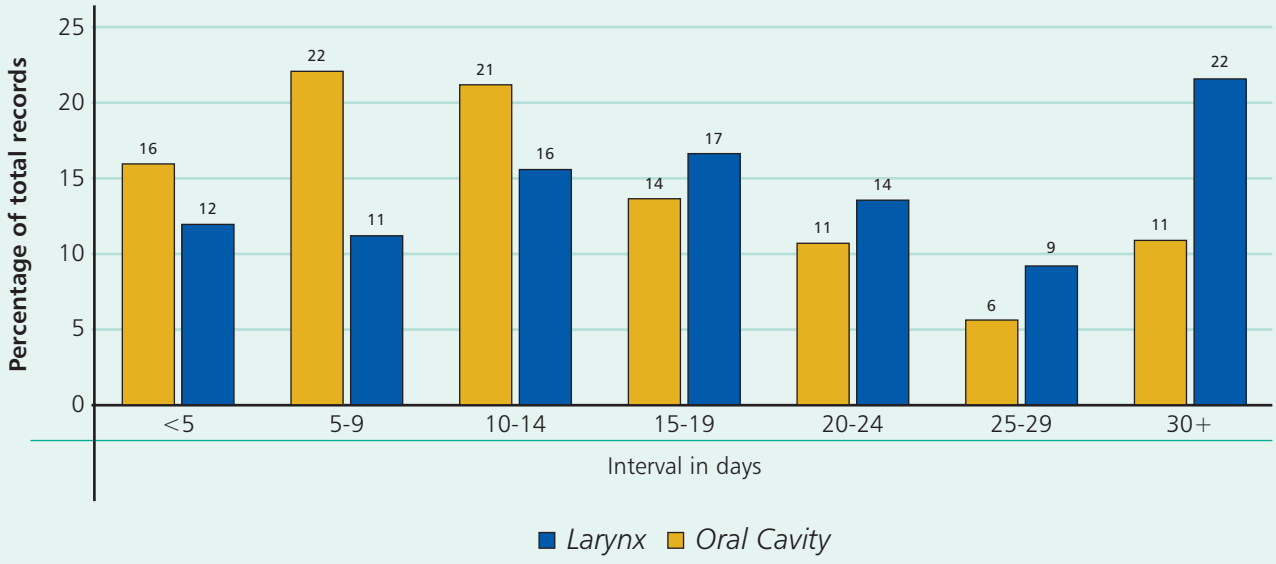
8.5.7 Interval from diagnosis to decision to treat

A number of key events occur in the cancer care pathway, and the following three graphs reflect time intervals along that path.

The point of diagnosis reflects the date upon which a biopsy was taken rather than the date histology was reported. The date of the MDT meeting where care options were discussed is reflected in the date MDT management was planned. The careplan agreed date is the date upon which the treating clinician and patient agree that care pathway. The date of 'primary care notification' is the date that communication was sent to the primary care practitioner.

8.5.7.1 Interval from diagnosis to MDT ('triage' date)

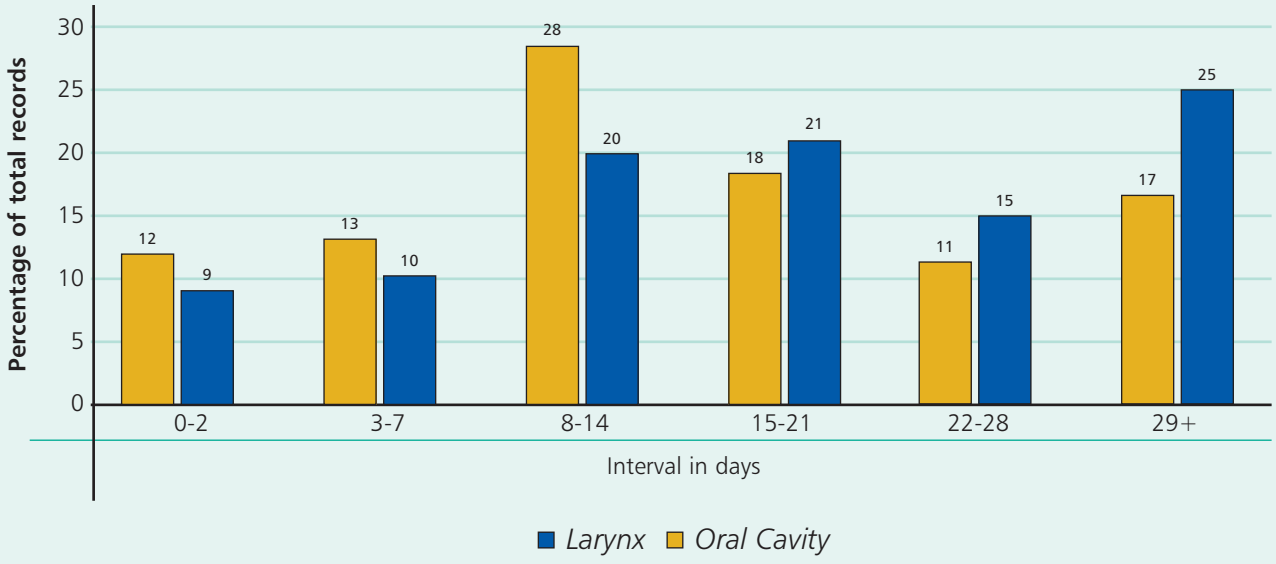
Figure 8.5.7.1.a: Interval from diagnosis to MDT ('triage' date)



- The median interval from diagnosis to MDT for larynx patients is 12 days and for oral cavity patients it is 17 days. Both of these times show small improvements from the first Annual Report. Within the 62 day target for the two week wait referral to treatment (effective in England, from 1 January 2006)[20 47] it would be expected that this interval may have reduced significantly.
- The interval from diagnosis to MDT reflects transfer of the biopsy to the laboratory, processing of the specimen and its reporting, receipt of the report and booking to the next MDT. An interim step can be a return to out patients when an unexpected diagnosis arises.
- 90 per cent of patients with laryngeal cancer and 78 per cent with oral cavity cancer have their MDT management planned in less than 30 days from the biopsy being taken. This may represent for oral cavity cancer a contribution from the delay to biopsy reporting seen in Figure 8.5.5.1.

8.5.7.2 Interval from diagnosis to date care plan agreed

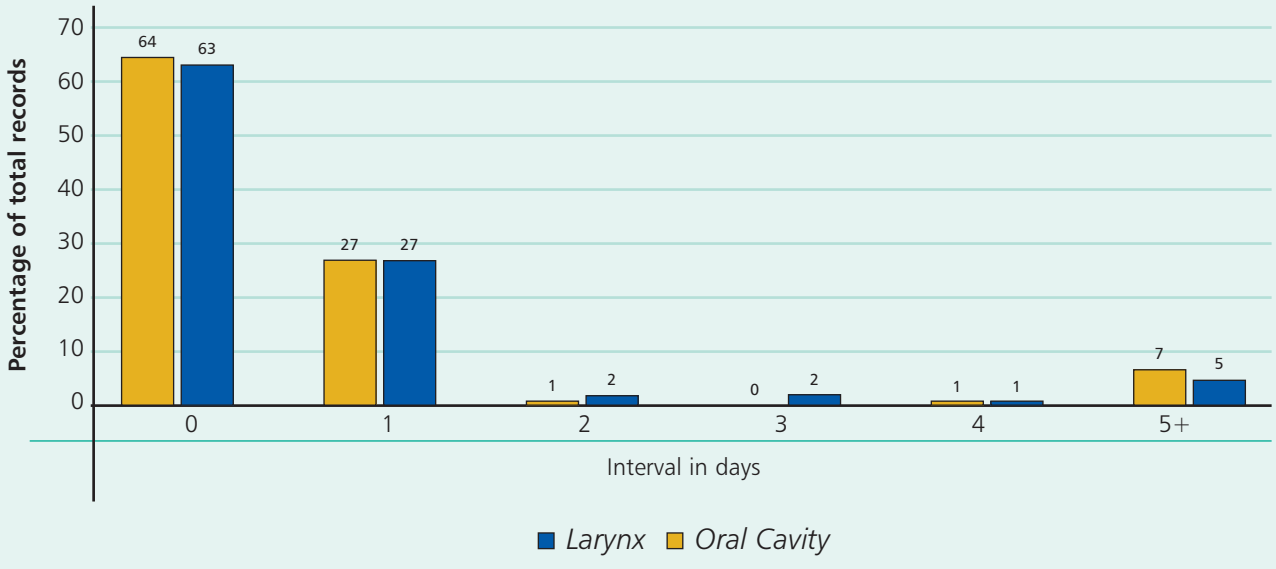
Figure 8.5.7.2.a: Interval from diagnosis to date care plan agreed



- The median interval from diagnosis to date careplan agreed for larynx patients is 14 days, for oral cavity patients it is 17 days.
- It is an accepted standard that all patients are discussed in an MDT.[19] This may reflect a non ideal pathway or may be a reflection of poor data quality.
- This chart appears to demonstrate that the majority of careplans are agreed within a short interval of the MDT meeting.

8.5.7.3 Interval from date care plan agreed to sending communication to primary care

Figure 8.5.7.3.a: Interval from date care plan agreed to sending communication to primary care



- Where this information is recorded, in over 60 per cent of cases, primary care notification occurred on the same day. However, only a third of cases had this information recorded. Best practice would be supported by confirmation that this standard is being achieved for all patients.

8.5.8 Number and percentage with histological confirmation prior to cancer careplan

Figure 8.5.8.a: Number of cases with histological confirmation prior to cancer careplan

Number of cases	Larynx	Oral cavity	All
Yes	200	149	349
No	18	71	89
Total	**218**	**220**	**438**

Figure 8.5.8.b: Percentage with histological confirmation prior to cancer careplan

As percentage of cases with both dates recorded	Larynx	Oral cavity	All
Yes	91.7	67.7	79.7
No	8.3	32.3	20.3
Total	**100**	**100**	**100**

- 521 patients can be associated with a diagnostic pathology date, and 438 of these patients have a careplan date (218 larynx, 220 oral cavity).
- Of these, 200 larynx (92 per cent) and 149 oral cavity (69 per cent) patients have histological confirmation recorded before the careplan.
- In head and neck cancer, it would be expected that all patients would have histological confirmation of a tumour prior to the agreement of a careplan and the results seem likely to reflect poor data quality. Further work is needed to understand this.
- There is a significant risk in proceeding to a cancer careplan without written histological confirmation of diagnosis, as rarely other conditions such as tuberculosis can mimic cancer.

8.5.9 Number and percentage with staging information recorded at time of cancer careplan

The percentage with staging information recorded at the time of cancer careplan reflects the percentage of patients with a careplan (indicated by record of 'management planned date' or non-blank 'careplan agreed date') with some recorded T, N or M diagnostic staging.

1,159 patients have a careplan date (recorded entry in careplan agreed date, or recorded entry in management planned date) (582 Larynx, 577 Oral Cavity).

972 have some diagnostic T, N or M staging recorded (502 Larynx, 470 Oral Cavity)

The tables summarise those 1,159 records with a careplan date:

Figure 8.5.9.a: Number of cases with staging information recorded at time of cancer careplan

Number	Larynx	Oral cavity	Total
Yes	429	418	847
No	153	159	312
Total	**582**	**577**	**1,159**

Figure 8.5.9.b: Percentage with staging information recorded at time of cancer careplan

Number	Larynx	Oral cavity	Total
Yes	73.7	72.4	73.1
No	26.3	27.6	26.9
Total	**100**	**100**	**100**

- Overall, of those patients with a recorded careplan, 73 per cent had recorded staging information. This figure is disappointing as no improvement has been seen year on year and in fact these figures remain similar to those found in the SWAHN 1 audit (1997-1999).[30]
- Staging of tumours is a critical part of the treatment pathway as well as being a key determinant of outcome, and is a key medical responsibility.
- All MDTs should be strongly encouraged to complete and validate staging information and validate outcome.

The Expert Panels are unanimous that all MDT's must ensure the recording of accurate staging information in 100 per cent of patients.

8.5.10 Percentage having chest imaging by chest x-ray (CXR) or chest computerised tomography (CT) prior to cancer careplan

483 patients have a recorded chest image by CXR or CT (253 Larynx and 230 Oral Cavity). 455 of these patients have recorded careplan date.

1,159 patients of the 1,443 in the cohort have a careplan date:

- Imaging data is recorded for 33.5 per cent of patients (483 of 1,443).
- Where both imaging and careplan data is recorded, 37.1 per cent of larynx cases (216 of 393) and 30.7 per cent of oral cavity cases (177 of 393) have chest imaging by x-ray or CT prior to careplan.
- This output was intended to reflect best practice where due to the recognised incidence of second primary lung cancers , chest imaging should occur prior to a cancer careplan in all patients.
- Whilst the level of completeness superficially appears poor for this item, it needs to be recognised that a design fault in the early version of the DAHNO application database did not allow correct recording of this information, and therefore results need to be interpreted with caution. This error has now been corrected.

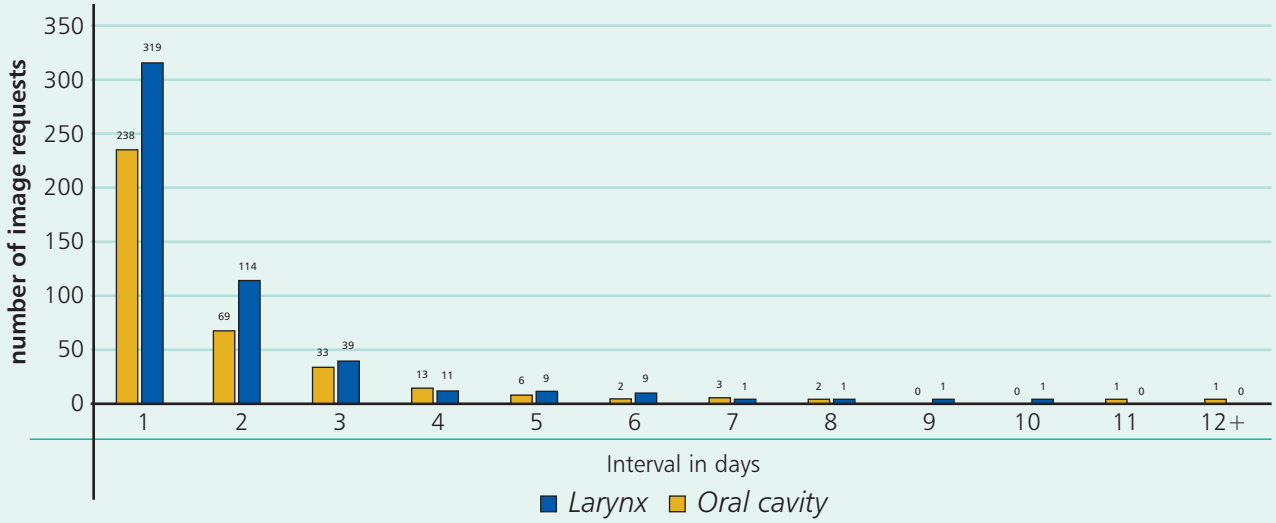
Synchronous malignancies of the chest can occur and have a significant impact on treatment options. Teams are encouraged to confirm that chest imaging has occurred in all head and neck cancer patients prior to planning treatment.

Figure 8.5.10.a: Number and percentage of cases having chest imaging by chest x-ray (CXR) or chest computerised tomography (CT) prior to cancer careplan

Imaging performed	Larynx	Percentage	Oral cavity	Percentage	Total	Percentage
Same day or before careplan	216	37.1	177	30.7	393	33.9
Imaging after careplan	25	4.3	36	6.2	61	5.3
No imaging recorded	341	58.6	364	63.1	705	60.8
Total	**582**	**100**	**577**	**100**	**1,159**	**100**

8.5.11 Interval from imaging request to date imaging performed (CT/MRI) contributory to pre-treatment staging complying with the Royal College of Radiologists' guidelines

Figure 8.5.11.a: Interval from imaging request to date imaging performed (CT/MRI) contributory to pre-treatment staging complying with the Royal College of Radiologists' guidelines



8.5.11.1 Imaging types where interval from imaging requests from data imaging is performed is four weeks or more

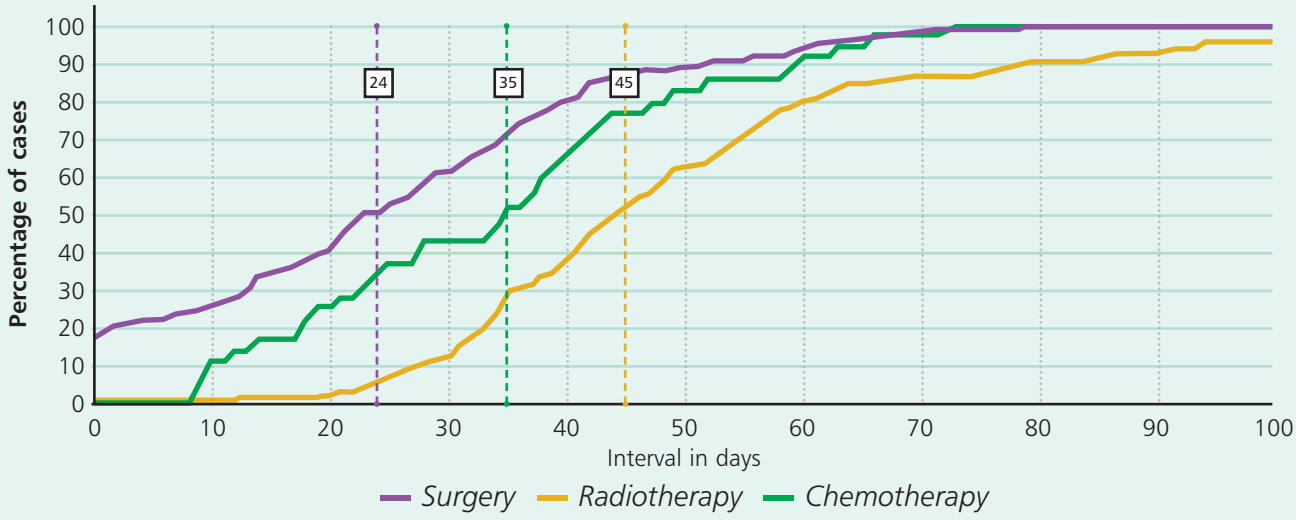
Figure 8.5.11.1.a: Imaging types where interval is four weeks or more

Imaging type	Larynx	Oral cavity
X-ray	5	11
CT scan	15	9
MRI scan	3	9
Ultrasound	1	5
Barium	1	0
Other	4	1
Total	**29**	**35**

- Progression of a patient along the cancer care pathway requires prompt imaging. A small but significant number of patients' pathways, from the evidence collected, show delays. The figure above demonstrates the imaging requests where a delay greater than four weeks occurred.
- In examining delays to CT scan this was found to mainly apply to three organisations. Similar delays within these organisations were found for both larynx and oral cavity. Feedback will be provided in the local reports.
- A radiologist should be a core member of an MDT and this integration process should accelerate access to imaging.
- This information will continue to be looked at more robustly in the future.

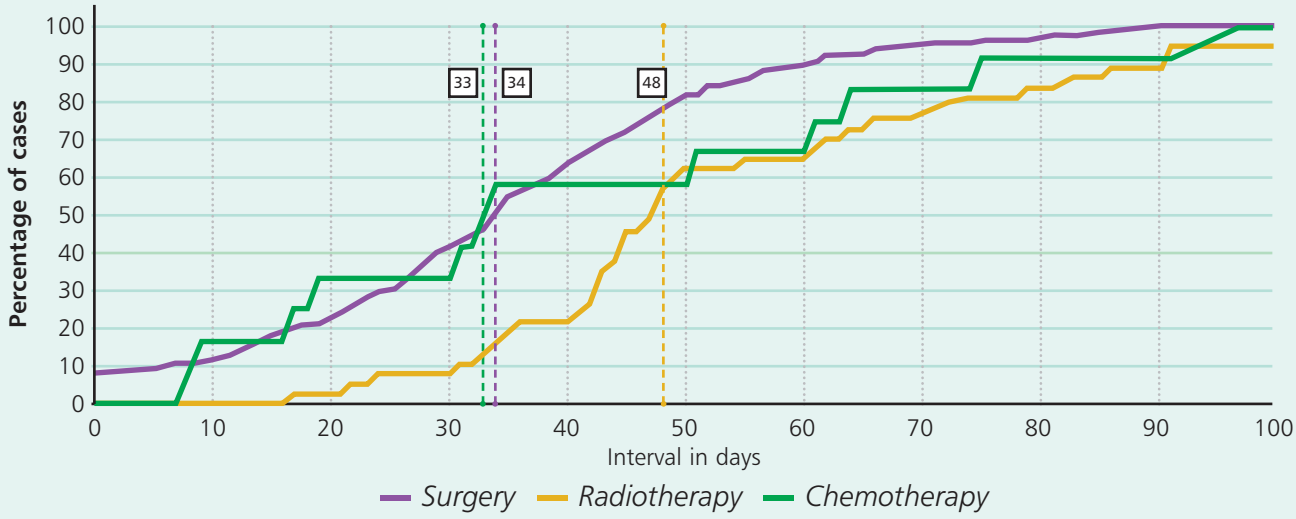
8.5.12 Interval from diagnosis to first definitive treatment

Figure 8.5.12.a: Larynx; Interval from diagnosis to first definitive treatment



- The majority of laryngeal cancer patients' first treatment is primary radiotherapy, with a median interval of 45 days from the point of diagnosis. For the smaller number who undergo surgery the median interval from diagnosis to first recorded treatment is 24 days. These show a reduction compared to the previous years data.

Figure 8.5.12.b: Oral Cavity; Interval from diagnosis to first definitive treatment



The majority of oral cavity cancer patients first treatment is surgery, with a median interval of 34 days from the point of diagnosis. For the smaller numbers who undergo primary radiotherapy, the median interval from diagnosis to first recorded treatment is 48 days.

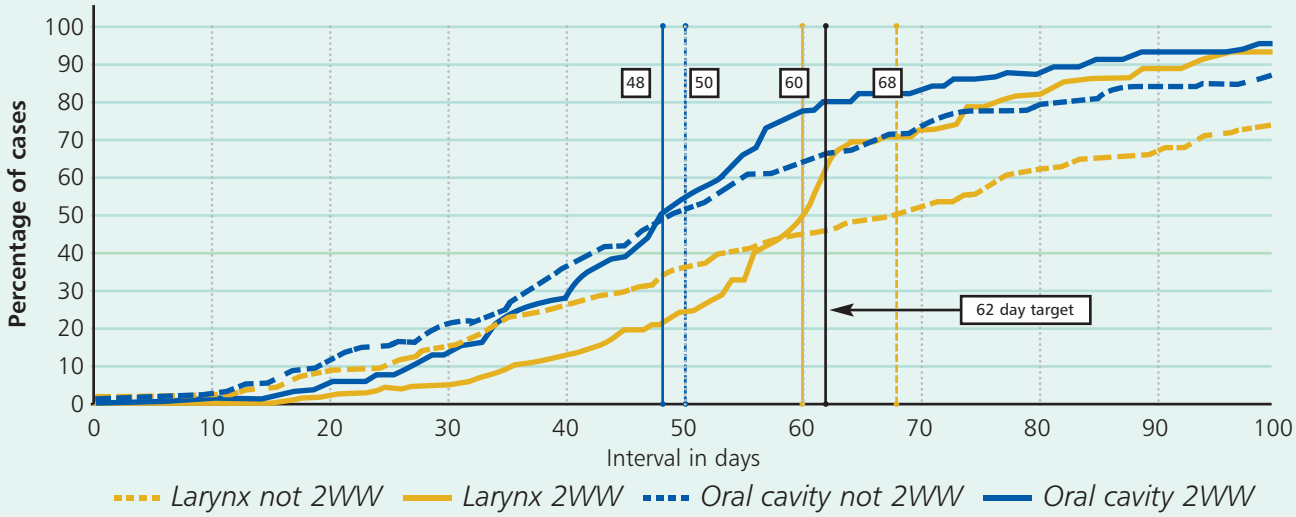
The results shown above, highlight that laryngeal and oral cavity cancer patients wait a similar interval for radiotherapy. The median time of 45 to 48 days is of concern for the ability to reach the 62 day target (England only).

Also, of concern, is that 50 per cent of patients are waiting for more than 45 days to commence radiotherapy, which may reflect resource limitations. This conclusion, that resource limitations particularly apply to radiotherapy, is supported by shorter access times for surgery in comparison for both sub-sites which share the initial common pathway to treatment decision.

Best practice suggests that primary radiotherapy should commence within 28 days of diagnosis.[49]

8.5.13 Interval from referral to first definitive treatment in England

Figure 8.5.13.a: Interval from referral to first definitive treatment in England



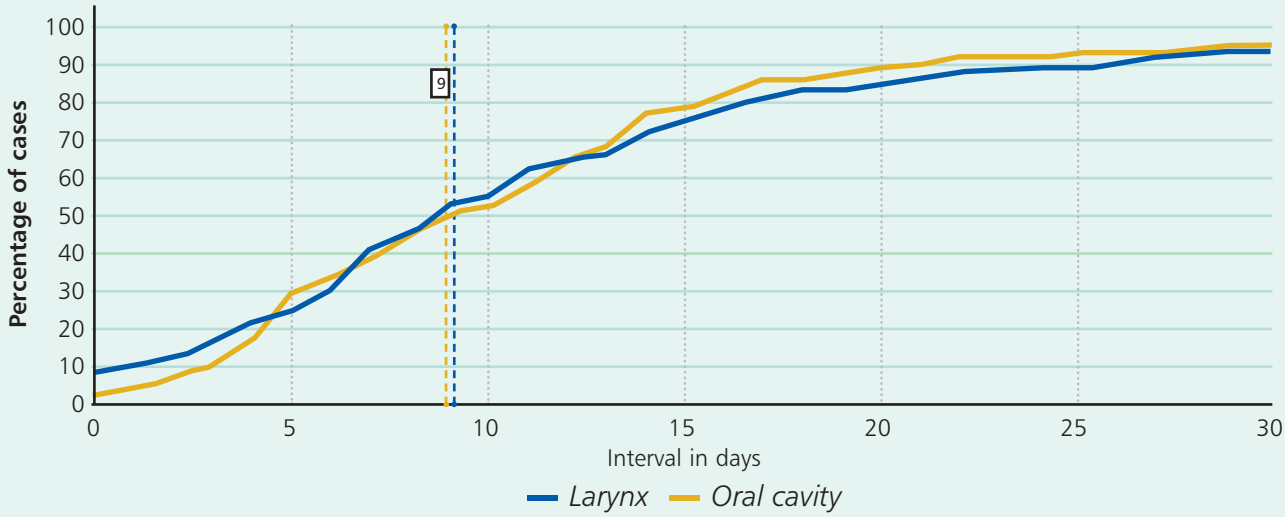
The two week wait target for urgent cancer referral applies to England and figures above only include patients from England.

The 62 day target came into effect in England on 1 January 2006 (which is part way through the audit period) and sets an expectation that patients referred under the two week wait will commence treatment in under 62 days.

- The median interval for larynx patients not referred via the two week rule was 68 days, but for two week wait patients it was 60 days.
- The median interval for oral cavity patients not referred via the two week rule was 50 days, but for two week wait patients it was 48 days.
- Whilst the median now falls less than 62 days for both larynx and oral cavity patients, considerable work remains to achieve this standard for all patients from date of referral to start of treatment.

8.5.14 Interval from surgical resection to reporting on resective specimen

Figure 8.5.14.a: Interval from surgical resection to reporting on resective specimen

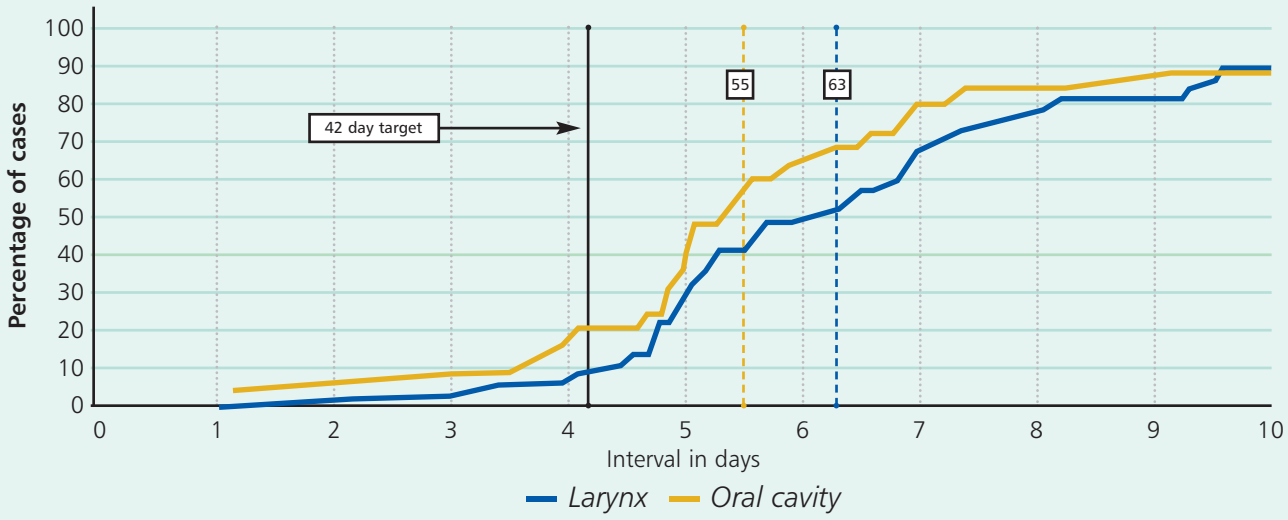


- The median interval to reporting for both larynx and oral cavity is 9 days.
- In oral cavity a consideration may be those specimens with composite bone resection which may require decalcification, but a provisional soft tissue margins report can be issued.
- However, the curves for larynx and oral cavity are very similar suggesting that this may be a resource issue. Further work is required to define this part of the treatment pathway.

8.5.15 Interval from date of surgery to post-operative radiotherapy

The first recorded surgery was considered. The first recorded radiotherapy after the surgery date was compared to it.

Figure 8.5.15.a: Interval from date of surgery to post-operative radiotherapy



- The median interval to post-operative radiotherapy was 55 days for larynx and 63 days for oral cavity. It should be noted the sample size is small.
- This part of the pathway reflects completion of post surgical healing, confirmation of resective pathology and preparation to proceed to start radiotherapy including production of a mould and planning.
- Tumour biology and previous work suggest that there should be less than six weeks to commencement of radiotherapy following surgery. [50] The results presented suggest considerable delay to commencing radiotherapy following both oral and laryngeal surgery.
- Further work is required to assess the contributory elements to this process.
- Pre-booking of adjuvant radiotherapy at the time of decision to treat may assist in reducing this interval.

8.6 Care provided - squamous cell carcinoma larynx

- 745 cases of larynx cancer were registered onto the DAHNO application.
- 408 (55 per cent) of these cases have either recorded treatment intent or a recorded careplan indicating palliative or supportive care.

Figure 8.6.a: Care provided - squamous cell carcinoma larynx

First recorded treatment	Early stage	Late stage	Late staged*	Total
Surgery	59	63	49	171
Radiotherapy	97	16	85	198
Chemotherapy	2	25	8	35
Specialist palliative care	0	3	1	4
Not recorded	97	52	188	337
Total	**255**	**159**	**331**	**745**

**Not staged – insufficient T, N, M for categorising early/late*

- The data for this item is deficient in nearly half of patients not having a primary treatment recorded and due to an absence of staging information.
- The established treatment for the majority of patients with laryngeal cancer in England and Wales is radiotherapy and this matches the results shown above.
- It is noted that an increased number of early staged patients have received surgery as their first definitive treatment, matching to the rising popularity of endolaryngeal resection.
- In advanced disease where appropriate, radical surgery (laryngectomy) with adjuvant radiotherapy is the curative treatment of choice, in those not suitable for surgery organ sparing protocols are being utilised.

8.6.1 Percentage having surgical resection with curative intent

- The intent was curative for 126 of the 171 cases with recorded surgery (74 per cent).
- Those with curative intent for surgery make up 31 per cent of the 408 with some recorded treatment, and 16.9 per cent of the total 745 cases.
- The 45 cases with intent other than curative show that: 3 are with palliative intent, 12 are with diagnostic intent, 13 are 'not known' and 17 have no intent recorded.

8.6.2 Percentage by category of clearance for surgical resection margins

- Only 31 per cent of records contained this information, thus few conclusions can be drawn.
- Where laser excision of early lesions has occurred, margins may be much narrower than for open surgery and thus obviate the classification used in data collection. However a comparison between laser resection and laryngectomy did not show marked differences in the small numbers recorded.

8.6.3 Percentage having pre-treatment dental assessment

- A pre-treatment dental assessment is recorded for less than 7 per cent of the 745 larynx registrations (51 patients) and is likely to reflect poor data quality.
- This is 13 per cent of the 408 cases with some record of treatment.
- An additional 107 larynx and oral cavity patients had a dental assessment but no date of treatment was recorded.

It is encouraging that the volume of data has increased and MDT's are recommended to collect this data.

The Expert Panel members would hope that this is not an accurate reflection of practice as it is extremely important to maintain good dental health throughout treatment.[51 52]

8.6.4 Percentage having pre-operative / pre-treatment speech and swallowing assessment (includes for laser cordectomy) and percentage having pre-operative / pre-treatment (includes radio and chemotherapy) dietetic assessment

- A pre-treatment speech and swallowing assessment is recorded for only 2 per cent of the 745 larynx registrations (17 patients) and is likely to reflect poor data quality.
- This is 4 per cent of the 408 cases with some record of treatment.
- Half of those having a speech and swallowing assessment had this after treatment had commenced.
- Patient representatives feel it is imperative that speech and swallowing and dietetic support is available to all patients with laryngeal cancer from diagnosis. The lack of appropriate professional support should be seen as a priority requirement. For those undergoing laryngectomy the speech therapist plays an important role in supporting choice in the method of restored speech.[53 54]
- An additional 91 larynx and oral cavity patients had a speech and language assessment but no date of treatment was recorded.
- A pre-treatment dietetic assessment is recorded for 5 per cent of the 745 larynx registrations (36 patients) and is likely to reflect poor data quality.
- This is 9 per cent of the 408 cases with some record of treatment.
- Over 80 per cent of those having a dietetic assessment had this prior to treatment.

Whilst the Expert Panel members believe that this is not a true reflection of current practice, they are aware of countrywide shortages in allied health professional posts to support cancer MDTs. The Expert Panel members realise this has significant resource implications, but their view is that speech and language therapists (SALT) and dietetic input is mandatory in all stages of laryngeal cancer.[55] They hope all MDTs strive to achieve this input. Resource bids would be supported by accurate data collection to quantify deficit and its correct capture onto the DAHNO application would identify the national profile of provision.

8.6.5 Percentage receiving each category of surgical procedure (including surgery to neck, surgical voice restoration)

- 172 patients have at least one surgical procedure recorded.
- Endolaryngeal microsurgical resection accounted for 39 per cent of surgical procedures and its frequency is rising (compared to 30 per cent last year) as an alternative to radical radiotherapy in early laryngeal cancer. The audit will continue to monitor this trend with interest.
- 34.3 per cent of surgical procedures were total laryngectomies, with only 9 per cent recorded as having primary surgical voice restoration. The Expert Panels felt that this was not representative of current clinical practice.
- The Expert Panel members would expect that the majority of patients (in excess of 80 per cent) undergoing this procedure would be counselled by a speech and language therapist pre-operatively and be offered primary surgical voice restoration. The availability of speech and language therapists may be a confounding factor but the absence of data collection above (Figure 8.6.5.a) limits the ability to resolve this.
- A small number of more extensive procedures are identified for very advanced tumours.

Figure 8.6.5.a: Percentage receiving each category of surgical procedure (including surgery to neck, surgical voice restoration)

Main categories of operation (patients may be counted in more than one category):

Larynx patients - surgery summary	Number	Percentage of 172 with surgery
Microlaryngeal resection	67	39.0
• of these 67 patients the number having neck dissection	2	
Laryngectomy	59	34.3
• of these 59 the number having supraglottic laryngectomy	3	
• of these 59, the number having neck dissection	35	
• of these 59, number having primary surgical voice restoration	3	
More extensive resection	5	
Neck dissections		
• (including those mentioned with laryngectomy and more extensive resection)*	48	27.9

** More extensive resection describes where a portion of the hypopharynx or oropharynx is removed beyond that normally included in a total laryngectomy*

It is important that all components of a surgical procedure are recorded to provide a true reflection of the breadth and complexity of surgical management.

8.6.6 Percentage having radical radiotherapy with curative intent

The established treatment for the majority of patients with laryngeal cancer in England is radiotherapy, and this matches to the results shown above.

- 204 cases have recorded radical (curative or adjuvant) radiotherapy. This is 85.7 per cent of the 238 with recorded radiotherapy.
- Those with radical radiotherapy make up 50 per cent of the 408 with some recorded treatment, and 27.4 per cent of the total 745 cases.
- The 34 other cases with recorded radiotherapy break down as: 8 with palliative intent and 26 with no intent recorded.
- The majority of patients have radiotherapy as primary treatment or as a planned adjuvant treatment within their initial cancer careplan. However, some patients, having undergone primary surgery, may be advised to proceed to post-operative radiotherapy based on adverse features evident in their resective histology report. Of the 25 patients having post surgical radiotherapy, 6 had undergone microlaryngeal resection, and the 10 in total laryngectomy. The former would suggest that margins at laser excision were incomplete and the latter could be influenced by both margins and adverse pathological features within the neck specimen.
- The Expert Panel members have concern that there may be deficiencies in capturing radiotherapy data. This still accounts for a small number of patients and thus will be looked at in future reports when sufficient cases have been captured.

8.6.7 Percentage having palliative treatment by type (i.e. radiotherapy, chemotherapy and surgery)

Of those presenting with advanced disease only small numbers would be expected to get true palliative treatment. It will be of interest in the future to assess what benefit they accrue, and whether they have received this as part of a clinical trial.

- 14 patients have recorded palliative treatment, 1.9 per cent of the total 745 registrations, 3.4 per cent of the 408 with recorded treatment.
- The 14 cases break down as: 3 cases of palliative surgery, 8 cases of palliative radiotherapy and 3 cases with palliative chemotherapy.

8.6.8 Percentage having chemotherapy (including categories such as 'adjuvant' and 'neo-adjuvant')

In the view of the Expert Panel members, there is no currently available evidence supporting the notion that chemotherapy in isolation improves long-term survival in laryngeal cancer.[14] There is, however, some evidence suggesting the benefits of concurrent chemoradiation,[56] and again it will be of interest to assess the benefits as they accrue with time.

- The intent was curative, adjuvant or neo-adjuvant for 29 of the 44 cases with recorded chemotherapy (66 per cent).
- These 44 cases are 10.8 per cent of the 408 with some recorded treatment, and 5.9 per cent of the total 745 cases.
- The 44 cases with a chemotherapy record break down by intent as: 24 curative, 2 adjuvant, 3 neo-adjuvant and 3 palliative. 12 cases had unknown intent or were uncoded.
- A review where it appeared that patients had chemotherapy as sole treatment in laryngeal cancer, identified that the majority were given as part of chemo radiotherapy regimen, but there were deficiencies in capturing the complete patient pathway.

8.6.9 Percentage referred to specialist palliative care team

There was only data in 5 cases of referral to a specialist palliative care team.

Specialist palliative care practitioners should be essential members of the core MDT team. Current processes of data capture may not pick up this activity as the provision can occur in a variety of non hospital organisations e.g. community and hospice care. The DAHNO Project Team will be interested to hear about successful methodology to integrate this element of data capture from Cancer Networks.

Data collection of care delivered along the whole patient pathway is a key requirement to understand the whole package of care. Networks are encouraged to facilitate this data collection.

8.6.10 Percentage receiving no specific treatment (including active monitoring category)

- 341 larynx cases have no recorded surgery, chemotherapy or radiotherapy
- None of these have 'supportive' as their careplan intent.
- 8 of the other cases have 'active monitoring' as the careplan intent.

8.6.11 Percentage of patients where careplan agreed matches careplan delivered

- 615 of the 745 registrations have a recorded careplan (82.6 per cent).
- 281 of 745 cases have a treatment record matching the careplan (45.7 per cent).

Note: Each patient can have more than one careplan and each careplan can list up to four planned treatments. Agreement between careplan and delivery was taken to require a match of every planned treatment in all recorded careplans with a recorded treatment.

8.7 Care provided - squamous cell carcinoma oral cavity

- 698 cases of oral cavity cancer were registered onto the DAHNO application.
- 598 cases have a careplan of which 292 (48.8 per cent) of these cases have a careplan with recorded treatment. This indicates either recorded treatment or a recorded careplan indicating palliative or supportive care.

Note: 410 cases have been used as 'the number of cases with recorded treatment' in the calculation of percentages in this Section.

Figure 8.7.a: Care provided - squamous cell carcinoma oral cavity

First recorded treatment	Early stage	Late stage	Not staged*	Total
Surgery	150	104	107	**361**
Radiotherapy	4	14	19	**37**
Chemotherapy	2	5	2	**9**
Chemotherapy and radiotherapy (same day)	1	1	1	**3**
Specialist palliative care	1	6	4	**11**
Supportive	1	1	2	**4**
Not recorded	50	69	154	**273**
Total	**209**	**200**	**289**	**698**

**Not staged – insufficient T, N, M for categorising as early / late*

- The established treatment for the majority of patients with oral cavity cancer in England is primary surgery, and this matches the results shown above.
- As only two-thirds of patients have records of their primary treatment and fewer again have details on the stage of the tumour, data analysis is purely descriptive.

8.7.1 Percentage having pre-treatment dental assessment

- A pre-treatment dental assessment is recorded for 16 per cent of the 598 oral cavity registrations with care plans (96 patients).
- This is 23 per cent of the 410 cases with some record of treatment.

The Expert Panel members would hope that this is not a true reflection of practice as it is extremely important to maintain good dental health throughout treatment.

8.7.2 Percentage having surgical resection with curative intent

- The intent was curative surgery for 311 of the 362 cases with recorded surgery (86 per cent).
- Those with curative surgery make up 76 per cent of the 410 with some recorded treatment, and 52 per cent of the total 598 cases with recorded care plans.
- The 51 cases with intent other than curative break down as: 2 with palliative intent, 3 with diagnostic intent, 9 with intent not known and 37 with intent not recorded.

8.7.3 Percentage by category of clearance for surgical resection margins

Figure 8.7.3.a: Care provided - squamous cell carcinoma oral cavity

Percentages of 311 cases recorded as surgery with curative intent.

Category	per cent
Not recorded	44.1
1. Margin involved	8.7
2. <1 mm clear	5.8
3. 1-5 mm clear	19.3
4. > 5 mm clear	19.0
5. Uncertain	1.9
8. Not applicable	0.6
9. Unknown	0.6

- Using the Royal College of Pathologists guidelines,[57] there was evidence in only 19 per cent of cases, of an acceptable clear margin.
- Only 53 per cent of resective pathology records show details on margins of normal tissue around the tumour, which limits the conclusions that can be drawn.
- Adequate resective margins are a predictor of both local recurrence and surgical adequacy.[58 59]
- Of the records completed, a quarter of them demonstrate margins greater than 5mm.

8.7.4 Percentage having pre-operative speech and swallowing assessment and percentage having pre-operative / pre-treatment dietetic assessment

- A pre-op speech and swallowing assessment is recorded for 6 per cent of the 598 oral cavity registrations with care plans (36 patients).
- This is 9 per cent of 410 cases with some record of treatment.
- A pre-treat dietetic assessment is recorded for 5 per cent of the 598 oral cavity registrations with care plans (32 patients).
- This is 8 per cent of the 410 cases with some treatment.

Whilst the Expert Panel members believe that this is not a true reflection of current practice, they are aware of countrywide shortages in allied health professional posts to support cancer MDTs. The Expert Panel members realise this has significant resource implications, but their view is that speech and language therapists (SALT) and dietetic input is mandatory. They hope all MDTs strive to achieve this input. Resource bids would be supported by accurate data collection to quantify deficit and its correct capture onto the DAHNO application would identify the national profile of provision.

8.7.5 Percentage receiving each category of surgical procedure (including surgery to neck, and flap repair)

Figure 8.7.5.a: Percentage receiving each category of surgical procedure (including surgery to neck, and flap repair)

Oral cavity patients - surgery summary	Count	Percentage of 365 patients with surgery
Floor of mouth excision	55.0	15.1
• of these 55, the number having neck dissection	28.0	
Buccal mucosa excision	22.0	6.0
• of these 22, the number having neck dissection	8.0	
Patients having tongue procedures	145.0	39.7
• of these 145, the number having neck dissection	67.0	
• patients having total glossectomy	2.0	
• patients having partial glossectomy	85.0	
• patients having excision lesion of tongue	58.0	
Patients having mandible procedures	62.0	16.9
• of these 62, the number having neck dissection	50.0	
• patients having extensive mandibulectomy	2.0	
• patients having hemimandibulectomy	17.0	
• patients having marginal mandibulectomy	30.0	
• patients having mandibulectomy or excision lesion	13.0	
Total maxillectomy	2.0	0.5
Partial maxillectomy	16.0	4.4
Comprehensive neck dissection (includes those listed previously)	24.0	6.6
Modified neck dissection (includes those listed previously)	39.0	10.7
Selective neck dissection (includes those listed previously)	107.0	29.3
Reconstruction mouth	67.0	8.2
• with flap	29.0	
• with primary closure	1.0	
• with buccal flap	3.0	
• with pectoralis major	4.0	
• with radial forearm	30.0	
Reconstruction mouth by cancer site		
• tongue	26.0	
• lip	1.0	
• gum	9.0	
• mouth floor	11.0	
• tongue and mouth floor	1.0	
• palate	4.0	
• cheek mucosa	7.0	
• mouth vestibule	2.0	
• retromolar trigone	6.0	

- Surgery followed by adjuvant radiotherapy – determined by histological findings is the commonest treatment modality for oral squamous cell carcinoma.
- Management of the N0 neck remains a contentious issue, but may be influenced by the requirement to enter the neck for reconstructive options.
- Of those patients undergoing floor of mouth excision only 50 per cent are recorded as having a neck dissection. The Expert Panels felt that this was a low figure compared to expected practice, but may reflect data quality issues.
- The number of reconstructions seems low, but may reflect that the method of data capture by multiple fields within the application, makes data capture difficult, and that the number of fields available is inadequate. A revision of the application has increased the number of procedural elements that can be recorded. Further review will be carried out in next years report. Surgical teams are encouraged to record all aspects of surgical care provided.

It is important that all components of a surgical procedure are recorded to provide a true reflection of the breadth and complexity of surgical management.

8.7.6 Percentage having radical radiotherapy (including brachytherapy, post-operative planned and unplanned)

- 63 cases have recorded radical (curative or adjuvant) radiotherapy. This is 80.8 per cent of the 78 cases with recorded radiotherapy.
- Those with radical radiotherapy make up 15 per cent of the 419 with some recorded treatment, and 9 per cent of the total 698 cases.
- No cases were recorded of brachytherapy, which is a recognised treatment for oral cavity cancer.
- The 15 other cases with recorded radiotherapy break down as: 9 with palliative intent and 6 with no intent recorded.
- The majority of patients have radiotherapy as primary treatment or as a planned adjuvant treatment within their initial cancer careplan. Some patients, having undergone primary surgery, may be advised to proceed to post-operative radiotherapy based on adverse features in their resective histology report. The Expert Panel members have concern that there may be deficiencies in capturing radiotherapy data. This accounts for a small number of patients and thus will be looked at in future reports when sufficient cases have been captured.

A general theme of the analysis is that the second phase of treatment is not being well captured. This may reflect MDT data capture processes. Teams are encouraged to capture all parts of the patients' careplan.

8.7.7 Percentage having palliative treatment by type (i.e. radiotherapy, chemotherapy, surgery)

- 13 patients have recorded palliative treatment, 1.9 per cent of the total 698 registrations, 3.1 per cent of the 419 with recorded treatment.
- The 13 cases break down as: 2 case of palliative surgery, 9 cases of palliative radiotherapy and 2 cases with palliative chemotherapy.

8.7.8 Percentage having chemotherapy (including categories such as 'adjuvant' and 'neo adjuvant')

In the view of the Expert Panel members, there is no currently available evidence supporting the notion that chemotherapy in isolation improves long-term survival in oral cavity cancer.[14] There is, however, some evidence suggesting the benefits of concurrent chemoradiation[59], and again it will be of interest to assess the benefits as they accrue with time.

- The intent was curative, adjuvant or neo-adjuvant for 21 of the 26 cases with recorded chemotherapy (80.8 per cent).
- These 21 cases are 5 per cent of the 419 with some recorded treatment, and 3 per cent of the total 698 cases.
- The 26 cases with a chemotherapy record breakdown by intent is: 17 curative, 1 neo-adjuvant, 3 adjuvant, 2 palliative and 3 with unknown intent.
- A review where it appeared that patients had chemotherapy as sole treatment in oral cavity cancer, identified that the majority were given as part of chemo radiotherapy regimen, but there were deficiencies in capturing the complete patient pathway.

8.7.9 Percentage referred to specialist palliative care team

There was only data in 12 cases of referral to a specialist palliative care team.

Specialist palliative care practitioners should be essential members of the core MDT team. Current processes of data capture may not pick up this activity as the provision can occur in a variety of non hospital organisations e.g. community and hospice care. The DAHNO Project Team will be interested to hear about successful methodology to integrate this element of data capture from Cancer Networks.

Data collection of care delivered along the whole patient pathway is a key requirement to understand the whole package of care. Networks are encouraged to facilitate this data collection.

8.7.10 Percentage receiving no specific treatment (including active monitoring category)

- 288 oral cavity cases have no recorded surgery, chemotherapy or radiotherapy.
- None of these have 'supportive' as their careplan intent.
- 4 of the other cases have 'active monitoring' as their careplan intent.

8.7.11 Percentage of patients where careplan agreed matches careplan delivered

- 602 of the 698 registrations have a recorded careplan (85.8 per cent).
- 273 cases of 602 have a treatment record matching the careplan (45.3 per cent).

Note: Each patient can have more than one careplan and each careplan can list up to four planned treatments. Agreement between careplan and delivery was taken to require a match of every planned treatment in all recorded careplans with a recorded treatment.

8.8 Patient outcomes

8.8.1 One year, two year and three year survival

The audit is too young to provide data for survival analyses.

However of the 1,443 cases 211 died during the data collection period which may be related to a variety of causes such as aggressive disease or deaths related to non cancer causes. Future reports will seek to examine death data in more detail.

8.8.2 Locoregional recurrence within one year and two years of diagnosis

The audit is too young to provide data for analysis of recurrence.

8.8.3 Number of treatment-related deaths (to include death within 30 days of surgery and/or within the same admission)

Figure 8.8.3.a: Number of treatment-related deaths (to include death within 30 days of surgery and/or within the same admission)

Description	Larynx	Oral cavity
Number of reported deaths within 30 days of surgery or with discharge destination 'death'	3	4
Of these patients , the number whose death followed diagnostic surgery	1	0
Of these patients, the number whose death followed recorded surgery with curative intent	1	3
Of the others, number whose death followed recorded surgery with no treatment intent recorded	1	1
Total number of patients with recorded curative surgery	**126**	**311**

• Overall, head and neck surgery appears a safe procedure.

Performing complex procedures in a predominantly elderly population with significant co-existent comorbidities will, however, inevitably lead to some deaths in the peri-operative period.

Further cycles of the audit will assist in providing nationally derived estimates of risk to patients and MDTs.

8.9 Clinical trials

Percentage entered into national clinical trials at cancer careplan has not been calculated.

In head and neck cancer, there is a paucity of national and international clinical trials. This remains an important area for development as trials become available.

9.0 Issues and recommendations

KEY

N = NETWORK **T = PROVIDER TRUST** **U = USERS** **P = PROFESSIONS** **D = DAHNO PROJECT**

Issues	Recommendations	Group to action
9.1 Clinical issues for multi-disciplinary teams A number of issues have been highlighted in the report. The Expert Panel had concerns about the care delivered, based on the data submitted. This may reflect the absence of collection rather true practice. However, the teams should assess their local delivery against the items opposite.	**Multi-disciplinary teams (MDTs) should:** • ensure the timeliness of pathways to meet national access targets • ensure the awareness and involvement of general dental practitioners and community dental services in urgent cancer referral processes • ensure that radiologists and specialist palliative care physicians are core members of the MDT • ensure that speech and language therapists and dieticians have active involvement in patient management and their care pathways • ensure that tumour staging (TNM) is confirmed and recorded prior to care planning and following surgical procedures • ensure that good dental health is maintained throughout treatment • ensure provision of surgical voice restoration counselling, pre treatment, for all patients having a laryngectomy • ensure provision of swallowing counselling, pre-treatment, for all patients who are about to undergo oral and oropharyngeal resective and or reconstructive surgery with free tissue transfer or partial laryngo-pharyngeal surgery • ensure that delays in commencement of radiotherapy/ chemotherapy – either as primary or adjunctive treatment- are minimised • ensure the recording of all treatments by identifying and documenting any reasons for the provision of chemotherapy in isolation as first line treatment, and where it is used as part of a chemo-radiation regime • facilitate meeting patient expectations that all care discussions are being made at a MDT, and head and neck cancer teams need to provide assurance around this important aspect of care delivery. This is unanimously supported by the Expert Panels • confirm that chest imaging has occurred in all head and neck cancer patients prior to planning treatment. Because synchronous malignancies of the chest can occur and have a significant impact on treatment options • ensure for accurate understanding of care pathways the importantance that all components of a surgical procedure are recorded to provide a true reflection of the breadth and complexity of surgical management • ensure data collection of care delivered along the whole patient pathway. This is a key requirement to understand the whole package of care delivered. Networks are encouraged to facilitate this data collection • note a general theme of the analysis, the second phase of treatment is not being well captured. This may reflect MDT data capture processes. Teams are encouraged to capture all parts of the patients' careplan.	**N** **T** **U**

KEY

N = NETWORK T = PROVIDER TRUST U = USERS P = PROFESSIONS D = DAHNO PROJECT

Issues	Recommendations	Group to action
9.2 Standards in clinical care Professional bodies, led by the British Association of Head and Neck Oncologists (BAHNO) and facilitated by the DAHNO Project Team, are evolving clinical standards.	Support and comply with evolving clinical standards as they become available in 2007.	N T U
9.3 Data quality and completeness The public should have access to accurate and risk adjusted clinical information.	To provide risk adjustment requires high levels and data quality and completeness. During audit rollout assumptions have been made that poor or missing data did not necessarily represent actual treatment given. Now that the audit is established this assumption is inappropriate and poor or missing data will be reflected as the treatment given: • Networks should increase local awareness and encourage compliance with the audit • provider Trusts should support local provision of data collection not only at commencement of treatment, but through follow up to include data on current treatment and rehabilitation • users and professionals should contribute to both support data collection and maintain consistency and quality of data collected.	N T U P U D
Absence of submission completeness on key fields e.g. certainty factor, performance status and comorbidity.	Users should familiarise themselves with all the items detailed within the audit, and use opportunities to attend bi-annual DAHNO workshops. The influence of factors such as comorbidity and performance status can have a significant effect upon treatment outcomes. Therefore all MDT's should collect these data set items.	N T
49 per cent of potential records submitted. Seven Cancer Networks have no submissions to this second annual report.	All Cancer Networks and constituent Provider Trusts not achieving high levels or any level of case submission should review their processes and support for submission of data. Best practice supporting data collection can be found at: www.ic.nhs.uk (or for DAHNO users www.DAHNO.com).	N T U P
Absence of staging information in submissions.	Awareness of clear recording of staging information prior to care planning should be increased to allow valid future comparison. This is a key medical responsibility and is centred around the MDT. All MDTs should be strongly encouraged to complete and validate staging information. Clinicians to note their role in enabling this.	N T U P N T U P
Absence of resective pathology information in submissions.	All MDTs should seek to accurately capture resective pathology information including pathological stage for every patient undergoing surgical treatment. This will enable true stage comparison of outcomes.	N T U P

KEY

N = NETWORK T = PROVIDER TRUST U = USERS P = PROFESSIONS D = DAHNO PROJECT

Issues	Recommendations	Group to action
9.4 Data process issues		
Continued identification of teams delivering cancer care.	All networks will be regularly contacted by the DAHNO Project Team to confirm contacts at Provider Trusts/hospitals that deliver head and neck cancer care.	D N
Absence of data submission on dietetic, speech and language, radiotherapy, palliative care activity.	Organisations should review the data collection process and ensure that it extends across the whole pathway. Scenarios from other users have been included in Appendix 10.	N T U
9.5 Application issues		
Iterative changes and updates to application.	Batch release of future application changes, with advance notice to users and training if required.	D U
Uploading from third party systems.	DAHNO Project to continue to advise IT providers of requirements to achieve successful upload.	D
Reporting of import errors.	DAHNO Project to proactively advise users via central import log of issues with import.	D U
9.6 Audit data to support clinical process		
Contemporaneous data collection	Although DAHNO is an audit process the timely collection of patient pathway data can support and expedite the overall delivery of patient care.	N T U

10.0 Future work

10.1 Risk adjustment

The successful first collection for the head and neck cancer audit has provided a wealth of data. Papers published in peer review medical journals indicate that a number of factors significantly influence the outcome in head and neck cancer treatment. These factors include patient demographics, tumour staging, whether the patient lives in an area of deprivation, ability to perform tasks of daily living (performance) and the presence of other illnesses (comorbidity).[33] Complete and comprehensive data collection allows the start of development of a model to clarify these risks.

To enable us to draw comparative conclusions between Cancer Networks and teams, it is important that like is compared with like. Both professionals and the public will wish to see evidence that teams are assessing their outcomes in light of evolving standards.

The DAHNO Project Team would strongly encourage collection of the items identified above to ensure, as future reports are produced, the building blocks for risk adjustment are in place.

In the future, the information from comparative audits may be Provider Trust identifiable and thus is key that a true risk adjusted comparison between organisations can be made.

10.2 Head and Neck Cancer Audit Phase II

Phase I has focused on the **delivery of appropriate primary treatment (including adjuvant therapy) in the management of head and neck cancer affecting the larynx and oral cavity by a multi-professional team, and delivery of care to agreed standards.**

During the data collection period 1 November 2006 to 31 October 2007, the phase I outputs remain unchanged and no additional requirements will be made.

Consultation on phase II outputs, to be introduced in November 2007, has completed and final discussions have commenced with the Head and Neck Clinical Reference Group (HNCRG) representing the professional bodies. A description of the outputs and system development will occur in early summer 2007, with testing prior to training sessions in September 2007.

10.3 Future publications and feedback to users

A summary report is in preparation and will be issued by the end of May 2007. It is intended for a wider audience beyond the professional head and neck community. It will be available on line at: www.ic.nhs.uk (and for DAHNO users at www.DAHNO.com).

All cancer Provider Trusts and Networks in England and Wales who have submitted sufficient cases in the current year (case number to be confirmed by the DAHNO Project Team) will receive a local feedback report comparing a selection of outcomes at their Provider Trust to the national peer average. This will be sent out in July 2007.

Cancer Provider Trusts in England and Wales with a lower level of submission will receive a letter to confirm contribution.

10.4 UK wide audit

The Healthcare Commission, in agreement with the Welsh Assembly Government, has commissioned this audit to cover Wales as well as England. Data from Welsh hospitals, collected and supplied through the CANISC system has been included in this report.

Professional members from elsewhere in the British Isles should be encouraged to participate in the audit where possible. The audit would benefit greatly from the widest possible participation. The IC is keen to facilitate and promote discussion and collaboration on national audit, and discussions are taking place to try to ensure commonality of datasets where they are being established outside of England.

10.5 Change in TNM Classification UICC 5 – UICC 6

The TNM classification is a worldwide benchmark for reporting the extent of malignant disease and is a major prognostic factor in predicting the outcome of patients with cancer. The objectives for cancer staging were defined by the International Union Against Cancer (UICC) TNM Committee almost 50 years ago and are still broadly applicable today. To keep pace with the modern demands of evidence-based practice, the UICC introduced a structured process for introducing changes to the TNM classification.

Cancer staging is one of the fundamental activities in oncology. The knowledge of the extent of disease is required to characterize the disease before selecting treatment. The key pieces of information needed for the management and reporting of results in patients with cancer are presenting site, histological type, and the anatomic extent of disease.

The TNM classification system has been modified over the years, mainly to improve its prognostic ability and to keep pace with the demands of clinical practice. The current (6th) edition was published in 2002 but DAHNO has continued to use the UICC 5 classification until there was wider acceptance of the changes incorporated into the UICC 6 classification. The project team and Head and Neck Clinical Reference Group representatives now feel that the DAHNO audit should move to the UICC 6 TNM classification and as such it is proposed that this change occurs during the current collection year, 1 November 2006 to 31 October 2007.

The major changes between UICC 5 and UICC 6 relate to the classification of late tumours i.e. T3 (glottic) and T4 tumours (all larynx and oral cavity) in an attempt to more accurately predict outcome in these advanced tumours with T4a and T4b categories now available.

For Oral Cavity, classification as a T4a tumour requires the following criteria to be met: the tumour invades through cortical bone, into deep/extrinsic muscle of tongue (genioglossus, hyoglossus, palatoglossus, and styloglossus), maxillary sinus, or skin of face. For classification as a T4b tumour, the following criteria need to be met: the tumour invades masticator space, pterygoid plates, or skull base, or encases internal carotid artery.

For glottic larynx classification as a T3 tumour is now defined as a tumour limited to larynx with vocal cord fixation and/or invades paraglottic space, and/or with minor thyroid cartilage invasion (e.g. inner cortex).

For larynx, classification as a T4a tumour requires the following criteria to be met: the tumour invades through the thyroid cartilage(all sites) and/or cricoid cartilage (glottic and subglottic) and/or invades tissues beyond the larynx, e.g. trachea, soft tissues of neck including deep/extrinsic muscle of tongue (genioglossus, hyoglossus, palatoglossus, and styloglossus), strap muscles, thyroid, oesophagus. For classification as a T4b tumour the following criteria need to be met: the tumour invades prevertebral space, mediastinal structures, or encases carotid artery.

The ability of UICC 6 to differentiate between cases where treatment may benefit the patient and those where it may not appears to be improved over the previous version, justifying the decision to move to this version of the staging classification.[63] It remains essential that complete staging data is recorded to allow accurate patient assessment both prior to treatment and for outcomes.

Prior to the date of introduction communication with users will be achieved by email, via the DAHNO website and whilst logging on to replicate databases. All units collecting head and neck data are urged to consider these changes and any impact there may be on their practices.

11.0 Conclusions

11.1 Feasibility

The contribution this year from Wales has confirmed the enthusiasm of head and neck professionals to see a national comparative audit delivered. The DAHNO Project provides an opportunity to achieve this.

The continuing support of the National Clinical Audit Support Programme (NCASP), Cancer Registries and the Healthcare Commission have enabled DAHNO to flourish.

11.2 Contribution rates

The increased level of case submission now means that half of oral cavity and larynx patients (England and Wales) had their care reported to the audit. This offers significant opportunities via the creation of a high quality medical database to act as both an information pool and a research tool to improve care.

11.3 Data Quality and Completeness

A number of items accurately and comprehensively completed are vital to allow true case comparison between treatments between different care providers. The Expert Panels noted that to achieve this it may be necessary to mandate key fields within the database.

All hospitals providing head and neck cancer care need to ensure that data collection is seen as a priority and should become an accepted part of providing care. DAHNO is not prescriptive about the methods used to capture data and recognises that organisations may follow different processes to achieve quality data collection. Examples of processes that have significantly facilitated data collection are given in Appendix 10 additionally further examples can be found at http://www.ic.nhs.uk (for DAHNO users www.DAHNO.com).

11.4 Validity

A comparison between data in the first annual report and the current report shows that the two populations studied have a high degree of similarity. This suggests that the early conclusions drawn and trends identified are valid across the population. However more comprehensive submission and completeness of data is required for confirmation.

11.5 Meeting access targets

Progress is seen in complying with access targets for treatments in England, but significant further work is still needed.

11.6 Multi-disciplinary team (MDT)

The multi-disciplinary team (MDT) represents a key opportunity for data collection.

Staging remains a key influence on outcome. The Expert Panels are unanimous that all MDTs must ensure the recording of staging information on 100 per cent of patients. Recording cancer site and accurate stage is a medical responsibility with best practice suggesting that this should be clearly documented at the MDT.

Factors such as comorbidity, and performance status also have a significant effect upon outcome. To allow future analysis to accurately risk adjust MDTs should record these factors on a routine basis.

11.7 Treatment

A general theme of the analysis is that the second phase of treatment is not being well captured. This may reflect the data capture process but teams are encouraged to capture all of the care delivered.

This year's report is again unable to describe aspects of pre-treatment dental assessment, pre-operative speech and swallowing evaluation and post operative dietetic assessment. This identifies the importance of data collection along the patient journey from all professionals to submit to comparative audit.

11.8 Radiotherapy

Patients have radiotherapy as primary treatment or as a planned adjuvant treatment within the initial careplan. Some patients having undergone primary surgery may be advised to proceed to postoperative radiotherapy following adverse features in their resective pathology report. The expert panel members have concern that there may be deficiencies entering radiotherapy data. This is an area of particular interest as there is a suggestion that uniform access to radiotherapy is not consistent for all patients, with some experiencing unacceptable delays.

The DAHNO Project will continue to seek ways of obtaining more comprehensive radiotherapy information.

11.9 Surgery

Some changes in the type and frequency of procedure delivered are seen. It is important that all aspects of the surgical procedure delivered are recorded. For those cases undergoing surgical management it is important that resective pathology is discussed at the MDT. The MDT is thus a key point to collect this information and surgical teams should contribute to this.

11.10 Patient Assurance

The rising contribution of professionals to this comparative audit and the outcomes so far recorded will hopefully provide a level of assurance for head and neck cancer patients undergoing treatment.

Future versions of this annual report will report outcomes by contributory provider trust and team, thus the importance of routine collection of factors that contribute to risk adjustment to allow true comparisons to be made. Similarly high levels of submission facilitate valid comparisons and provide an opportunity to demonstrate to patients an organisations commitment to clinical governance and proof of the quality of its services.

Appendix 1

List of Cancer Networks and Provider Trusts providing head and neck cancer care in England and participation status

Note: the following represents a list of the Cancer Networks and their advised Provider Trusts that refer, treat or diagnose head and neck cancer patients, and who have submitted patient details. This table does not include details of Provider Trusts that have had their information submitted by another Trust.

Good data completeness score

Poor data completeness score

No data completeness score due to lack of submissions

Trust known to have data but unable to send due to technical issues

Cancer Network Name	Provider Trust Name (colour coded by score)
ENGLAND	
Derby Burton	**Derby Hospitals NHS Foundation Trust**
	Burton Hospitals NHS Trust
Greater Manchester and Cheshire	**Christie Hospital NHS Trust**
	Wrightington, Wigan and Leigh NHS Trust
	Bolton Hospitals NHS Trust
	Salford Royal Hospitals NHS Trust
	Trafford Healthcare NHS Trust
	Central Manchester and Manchester Children's University Hospitals NHS Trust
	University Hospital Of South Manchester NHS Foundation Trust
	Stockport NHS Foundation Trust
	East Cheshire NHS Trust
	Mid Cheshire Hospitals NHS Trust
	Tameside and Glossop Acute Services NHS Trust
	Pennine Acute Hospitals NHS Trust
Humber and Yorkshire Coast	**Hull and East Yorkshire Hospitals NHS Trust**
	Northern Lincolnshire and Goole Hospitals NHS Trust
	Scarborough and North East Yorkshire Health Care NHS Trust
Lancashire and South Cumbria	**Blackpool, Fylde and Wyre Hospitals NHS Trust**
	Morecambe Bay Hospitals NHS Trust
	Lancashire Teaching Hospitals NHS Trust
	East Lancashire Hospitals NHS Trust

Cancer Network Name	Provider Trust Name (colour coded by score)
Merseyside and Cheshire	Clatterbridge Centre for Oncology NHS Trust
	North Cheshire Hospitals NHS Trust
	Royal Liverpool and Broadgreen University Hospitals NHS Trust
	St Helens and Knowsley Hospitals NHS Trust
	Aintree University Hospitals NHS Foundation Trust
	Wirral Hospital NHS Trust
	Countess of Chester Hospital NHS Foundation Trust
	Southport and Ormskirk Hospital NHS Trust
Northern	North Cumbria Acute Hospitals NHS Trust
	City Hospitals Sunderland NHS Trust
	The Newcastle Upon Tyne Hospitals NHS Trust
	South Tyneside Health Care NHS Trust
North Trent	Sheffield Teaching Hospitals HNS Trust
	Barnsley District General Hospital NHS Trust
	Doncaster and Bassetlaw Hospitals NHS Foundation Trust
	Chesterfield and North Derbyshire Royal Hospital NHS Trust
	Rotherham General Hospitals NHS Trust
Teesside, South Durham and North Yorkshire	South Tees Hospitals NHS Trust
	County Durham and Darlington Acute Hospitals NHS Trust
Yorkshire	Leeds Teaching Hospitals NHS Trust
	Bradford Teaching Hospitals NHS Foundation Trust
	York Hospitals NHS Trust
Kent and Medway	Maidstone and Tunbridge Wells NHS Trust
	East Kent Hospitals NHS Trust
	Medway NHS Trust
	Dartford and Gravesham NHS Trust
	Queen Victoria Hospital NHS Foundation Trust
Mount Vernon	The Hillingdon Hospital NHS Trust
	West Hertfordshire Hospitals NHS Trust
	East and North Hertfordshire NHS Trust
	Luton and Dunstable Hospital NHS Trust

Cancer Network Name	Provider Trust Name (colour coded by score)
North East London	Barts and The London NHS Trust
	Barking, Havering and Redbridge Hospitals NHS Trust
	The Princess Alexandra Hospital NHS Trust
	Homerton University Hospital NHS Foundation Trust
	Newham Healthcare NHS Trust
	Whipps Cross University Hospital NHS Trust
North London	Royal Free Hampstead NHS Trust
	University College London Hospitals NHS Trust
	Barnet and Chase Farm Hospitals NHS Trust
	North Middlesex University Hospital NHS Trust
South Essex	Southend Hospital NHS Trust
	Basildon and Thurrock University Hospitals NHS Foundation Trust
South West London	The Royal Marsden NHS Foundation Trust
	St George's Healthcare NHS Trust
	Mayday Healthcare NHS Trust
	Epsom and St Helier University Hospitals NHS Trust
West London	Hammersmith Hospitals NHS Trust
	West Middlesex University Hospital NHS Trust
	North West London Hospitals NHS Trust
	Chelsea and Westminster Healthcare NHS Trust
	Ealing Hospital NHS Trust
	Kingston Hospital NHS Trust
	St Mary's NHS Trust
3 Counties	Hereford Hospitals NHS Trust
	Worcester Acute Hospitals NHS Trust
	Gloucestershire Hospitals NHS Trust

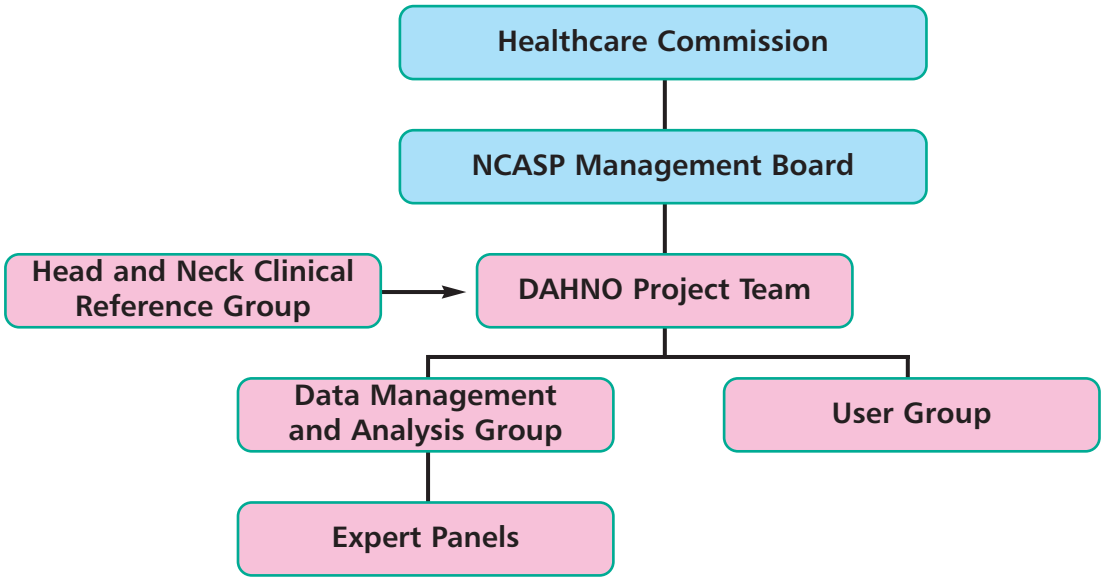
Cancer Network Name	Provider Trust Name (colour coded by score)
Avon Somerset and Wiltshire	Yeovil District Hospital NHS Foundation Trust
	North Bristol NHS Trust
	Royal United Hospital Bath NHS Trust
	Swindon and Marlborough NHS Trust
	United Bristol Healthcare NHS Trust
	Taunton and Somerset NHS Trust
Dorset	Poole Hospitals NHS Trust
	Royal Bournemouth and Christchurch Hospitals NHS Trust
	West Dorset General Hospitals NHS Trust
Peninsula	Plymouth Hospitals NHS Trust
	Royal Devon and Exeter NHS Foundation Trust
	Northern Devon Healthcare NHS Trust
	South Devon Healthcare NHS Trust
	Royal Cornwall Hospitals NHS Trust
Arden	University Hospitals Coventry and Warwickshire NHS Trust
	George Eliot Hospital NHS Trust
	South Warwickshire General Hospitals NHS Trust
Leicestershire, Northamptonshire and Rutland	University Hospitals Of Leicester NHS Trust
	Northampton General Hospital NHS Trust
	Kettering General Hospital NHS Trust
Greater Midlands	University Hospital of North Staffordshire NHS Trust
	Shrewsbury and Telford Hospital Trust
	The Royal Wolverhampton Hospitals NHS Trust
	Mid Staffordshire General Hospitals NHS Trust
Pan Birmingham	University Hospital Birmingham NHS Trust
	Heart Of England NHS Foundation Trust
	Sandwell and West Birmingham Hospitals NHS Trust

Cancer Network Name	Provider Trust Name (colour coded by score)
Mid Anglia	Ipswich Hospital NHS Trust
	Essex Rivers Healthcare NHS Trust
	Mid-Essex Hospital Services NHS Trust
Norfolk and Waveney	Norfolk and Norwich University Hospital NHS Trust
	James Paget Healthcare NHS Trust
	Papworth Hospital NHS Trust
Thames Valley	Royal Berkshire and Battle Hospitals NHS Trust
	Oxford Radcliffe Hospitals NHS Trust
	Heatherwood and Wexham Park Hospitals NHS Trust
	Buckinghamshire Hospitals NHS Trust
	Milton Keynes General Hospital NHS Trust
West Anglia	Cambridge University Hospitals NHS Foundation Trust
	Peterborough and Stamford Hospitals NHS Foundation Trust
	Hinchingbrooke Healthcare NHS trust
	Bedford Hospital NHS Trust
	Kings Lynn and Wisbech Hospitals NHS Trust
	West Suffolk Hospitals NHS Trust
Mid Trent	Nottingham University Hospitals NHS Trust
	Nottingham City Hospital NHS Trust
	Sherwood Forest Hospitals NHS Trust
	United Lincolnshire Hospitals NHS Trust
Central South Coast	Southampton University Hospitals NHS Trust
	Salisbury Healthcare NHS Trust
	Isle of Wight Healthcare NHS Trust
	Royal West Sussex NHS Trust
	Portsmouth Hospitals NHS Trust

Cancer Network Name	Provider Trust Name (colour coded by score)
South East London	The Lewisham Hospital NHS Trust
	Guy's and St Thomas' NHS Trust
	Bromley Hospitals NHS Trust
Surrey, West Sussex and Hants	Basingstoke and North Hampshire NHS Foundation Trust
	Royal Surrey County Hospital NHS Trust
	Surrey and Sussex Healthcare NHS Trust
	Frimley Park Hospital NHS Trust
	Ashford and St Peter's Hospitals NHS Trust
Sussex	Brighton and Sussex University Hospitals NHS Trust
	Worthing and Southlands Hospitals NHS Trust
	East Sussex Hospitals NHS Trust
WALES	
North Wales Cancer Network	Conway and Denbighshire NHS Trust
	North West Wales NHS Trust
	North East Wales NHS Trust
South East Wales Cancer Network	Gwent Healthcare NHS Trust
	North Glamorgan NHS Trust
	North Glamorgan NHS Trust
	Cardiff and Vale NHS Trust
	Velindre NHS Trust
South West Wales Cancer Network	Swansea NHS Trust
	Bro Morgannwg NHS Trust
	Swansea NHS Trust
	Carmarthenshire NHS Trust
	Pembrokeshire and Derwen NHS Trust

Appendix 2

Project structure and membership



Parties involved in the head and neck cancer audit:

NCASP Management Board	The NCASP Management Board has management responsibility for the NCASP Programme and all Project Implementation Groups and Service Management Groups
Project Team	**Remit:** Provides the overall direction for the service and manages the delivery of the project. They manage the issues and risks as well as change requests, maintain the link to Secondary User Services (SUS) to develop the requirements and assist facilitation of migration, agree communication objectives and link to the Communication Team to ensure communication delivery. The Board is accountable for the success of the Project and is responsible for the management of all Project groups. **Accountable to:** The NCASP Management Board. Representation: Healthcare Commission, lead head and neck cancer clinicians, project manager, audit system developer, cancer registries, Cancer Action Team, DAHNO User Group, DAHNO Helpdesk, Clinical Oncology. **Meeting frequency:** Monthly. **Membership:** Richard Wight-Consultant ENT Surgeon and Chair of the BAHNO Audit Committee (Project Team Chair), Graham Putnam Consultant Maxillofacial Surgeon (Project Team Vice Chair), Paul Theato DAHNO Project Manager, Steve Dean Senior Project Manager (Cancer Audits), Helen Laing Clinical Audit Commissioning Manager, Ronnie Brar DAHNO Developer, Simon Netley Helpdesk Support Officer, Chris Carrigan National Lead for cancer registries, John Browne Lecturer in Outcome Assessment, Phil Hill Cancer Action Team, Chris Nutting Consultant and Hon. Senior Lecturer in Clinical Oncology, David Cunningham CCAD Project Manager, Mary Boden DAHNO Project Support Officer.

Head and Neck Clinical Reference Group	**Remit:** Agreement and ownership of the outcome measures and related data items; provision of support to the Project Team; 'marketing' of the DAHNO Audit (across the professions involved); and governance of use of the data and nature of reporting. **Accountable to:** The Project Team and their professional bodies. **Representation:** National groups involved in head and neck cancer care. **Meeting frequency:** Two meetings per year. **Membership:** Richard Wight Consultant ENT Surgeon and Chair of the BAHNO Audit Committee (Project Team Chair), Graham Putnam Consultant Maxillofacial Surgeon (Project Team Vice Chair), Paul Theato DAHNO Project Manager, Steve Dean Senior Project Manager (Cancer Audits), Mary Boden DAHNO Project Support Officer, Ian Martin Oral and Maxillofacial Surgeon British Association of Head and Neck Oncologists, Patrick Bradley Head and Neck Oncological Surgeon, Andrew Fishburn-British Association of Head and Neck Oncology Nurses, John Weighill British Association of Otolaryngology, Head and Neck Surgeons, Patrick Magennis British Association of Oral and Maxillofacial Surgeons, Sarah Cameron British Dietetic Association, Paul Speight British Society for Oral and Maxillofacial Pathology, RD Errington Clinical Oncology, Gerry Humphris Clinical Psychology Helen Laing Healthcare Commission Gerry Robertson Lead Clinician for Scotland head and neck cancer data, Christine Piff Let's Face It, Jean Fraser National Association of Laryngectomee clubs, Ged Corcoran Palliative Care Association, AJ Downes Royal College of General Practitioners, JFC Olliff Royal College of Radiologists, Tim Helliwell Royal College of Pathologists, Jo Patterson Royal College of Speech and Language Therapists, Professor Mike Richards National Cancer Director Cancer Action Team, Martin Old NCASP Programme Manager.
Data Management and Analysis Group	**Remit:** Manage requests for data received by the DAHNO Project and the analysis of data collected as well as delivering the annual report and Provider Trust analysis reports and feedback. **Accountable to:** The Project Team. **Representation:** Lead clinicians, project manager, cancer registries, data analysis specialist, IC Caldicott Guardian. **Meeting frequency:** Four to five meetings per year. **Membership:** Richard Wight Consultant ENT Surgeon and Chair of the BAHNO Audit Committee (Project Team Chair), Graham Putnam Consultant Maxillofacial Surgeon (Project Team Vice Chair), Paul Theato DAHNO Project Manager, Steve Dean Senior Project Manager (Cancer Audits), Ronnie Brar DAHNO Developer, Chris Carrigan National Cancer Registration Coordinator, Henrik Møller National Lead for Cancer Registries, Andy Pring Senior Information Analyst, Sandra Edwards Cancer Intelligence Analyst, Patrick Bradley Head and Neck Oncologic Surgeon, Christine Piff CE Let's Face It charity, Jo Patterson Macmillan Speech and Language Therapist, Patrick Magennis Consultant Oral and Maxillofacial Surgeon, Mary Boden DAHNO Project Support Officer.

Expert Panels	**Remit:** Provide clinical expertise for the development of the annual reports. **Accountable to:** The Data Management and Analysis Group. **Representation:** Lead clinicians in oral cavity and larynx cancer, Cancer Registries. **Meeting Frequency:** Two to three times per year. **Membership:** Patrick Bradley Head and Neck Oncologic Surgeon, Terry Jones ENT Surgeon, Mark Watson ENT Surgeon, David Howard ENT Surgeon, Jon Hayter Consultant Maxillofacial Surgeon, Iain McVicar-Consultant Maxillofacial Surgeon, Cyrus Kerawala Consultant Oral and Maxillofacial Surgeon, Simon Rogers Consultant Maxillofacial Surgeon and Honorary Reader in OMFS, Chris Nutting Consultant and Hon. Senior Lecturer in Clinical Oncology, Richard Wight Consultant ENT Surgeon and Chair of the BAHNO Audit Committee (Project Team Chair), Graham Putnam Consultant Maxillofacial Surgeon (Project Team Vice Chair), Paul Theato DAHNO Project Manager, Mary Boden DAHNO Project Support Officer
User Group	**Remit:** User representatives who participate in the DAHNO Audit that ensure the views of users are appropriately reflected in the Project. **Accountable to:** The Project Team. **Representation:** Users spanning all types of job role related to head and neck cancer audit at a Cancer Network and Provider Trust level nationwide. **Meeting frequency:** Quarterly. **Membership:** To be confirmed.
Helpdesk	**Remit:** To respond to and manage technical and clinical queries from users and provide ad hoc training and support to networks and Provider Trusts. **Accountable to:** The DAHNO Project Team. **Team members:** Gary Sargent and Sandy Garrity.
NCASP Team	NCASP Team including Programme Manager Martin Old and NCASP Communications Manager Charlotte Tye.
Early adopters	Provider Trusts within the following Cancer Networks were early adopters for the rollout of the DAHNO application: Northern; Teesside and Yorkshire; West Anglian; Arden; Avon, Somerset and Wiltshire and North London.
Previous staff	Beverley Meeson, Steve Wise, Toby Hewlett, Steven Cooper, Rob Cairney, Anna-Marie O'Connor, Lynne Skyrme and Kerry Agar.
Other contributors	Jonathan Boyce and Dick Waite at the Healthcare Commission.

Appendix 3

Contributing professional organisations

There are many organisations that have contributed and continue to contribute to the audit. They are listed below.

- British Association of Head and Neck Oncologists
- British Association of Head and Neck Oncology Nurses
- British Association of Oto-larynologists - Head and Neck Surgeons (ENT UK)
- British Association of Oral and Maxillofacial Surgeons
- British Association of Plastic Surgeons
- British Dental Association
- British Dietetic Association
- British Society for Oral and Maxillofacial Pathology
- National Association of Laryngectomee Clubs
- Royal College of Surgeons
- Royal College of General Practitioners
- Royal College of Radiologists
- Royal College of Pathologists
- Royal College of Speech and Language Therapists
- Palliative Care Association
- Let's Face It
- UK Association of Cancer Registries
- Representatives from clinical oncology
- Representatives from clinical psychology

Appendix 4

Technical infrastructure

DAHNO system requirements and recommendations

Requirement	Details
IBM Lotus Notes® version	Release client 6.0 or above
Operating system	Microsoft® Windows 95 Second Edition Microsoft® Windows 98 Microsoft® Windows NT Version 4.0 (with Service Pack 6a) Microsoft® Windows 2000 Professional Edition Microsoft® Windows XP
Protocol	TCP / IP (IBM Lotus Notes® can use other protocols but the DAHNO application is configured for TCP / IP only)
Memory (RAM)	Microsoft® Windows 98 Second Edition – 64mb minimum, 128 mb highly recommended Microsoft® Windows 98 – 64 mb minimum, 128mb highly recommended Microsoft® Windows NT Version 4.0 (with Service Pack 6a) – 64mb minimum, 128mb highly recommended Microsoft® Windows 2000 Professional Edition – 128mb minimum, 256 highly recommended Microsoft® Windows XP – 128mb minimum, 256 highly recommended
Disk space	275mb free for IBM Lotus Notes® install Additional 750mb required as a minimum for DAHNO application databases Total 1gb minimum
Display	Colour monitor and graphics card capable of displaying 1024 x 768 pixels with at least 256 colours

The DAHNO application technical infrastructure is closely linked to the methodology employed in the national heart disease audits – the Central Cardiac Audit Database (CCAD). The success of these audits contributed to the decision to use the same structure for the DAHNO application. The client-server architecture was chosen specifically to overcome the limitations of web-based applications in an environment with poor connectivity. Although the NHS network has improved enormously since CCAD began collecting data in 2000, there are still situations where a client-server system has advantages, for instance when the network is down or the application is installed on a mobile laptop platform with only an occasional NHSnet connection. In addition, software updates are communicated automatically to users when they connect to the central servers to exchange local data, making the systems easy to maintain.

The architecture chosen for the DAHNO application and CCAD has proven robust and secure – there have been no breaches of patient confidentiality since data collection began despite collection of data on nearly a million patients. The level of encryption (of local databases and of data transmissions) ensures database security. The DAHNO/CCAD platform represents the highest level of security in the NHS environment.

Appendix 5

Dataset and manual

Data collected in DAHNO strictly adheres to the National Cancer Dataset including the head and neck appendage (www.ic.nhs.uk) or (www.DAHNO.com)

A dataset is a description of the data items, their definitions and the allowable entries that are collected when a patient undergoes an event or procedure. Hospitals have a choice of either entering the minimum amount of data required for oral cavity and larynx (minimum dataset) or entering a wider range of data that will not be analysed by the audit but can be used as reference material by the hospital itself.

The following tables are the dataset items from version 4.0 of the National Cancer Dataset for the first phase of the head and neck cancer audit.

Dataset items

ID	Data Item
1	**Demographics**
1.1	NHS number [NHS Number]
1.2	Local patient identifier [Hospital Number]
1.3	Organisation code (code of provider) [Provider Code]
1.4	Carespell identifier [Unique Care Spell Number]
1.5	Patient family or surname [Surname]
1.6	Patient forename of personal name [Forenames]
1.8	Postcode of usual address (at diagnosis) [Postcode at Date of Diagnosis]
1.9	Sex [Sex]
1.10	Birth date [Date of Birth]
1.12	Code of GP practice (Registered GMP) [GP Practice Code]
2	**Referrals**
2.1	Source of referral for cancer [Source of Referral]
2.3	Referral code [Referred by]
2.4	Cancer referral priority type [Priority of Referral]
2.5	Cancer referral decision date [Date of Decision to Refer]
2.6	Referral request received date [Date of Receipt of Referral]
2.9	Date first seen [Date First Seen]
2.10	Delay reason referral to first seen (cancer)
2.11	Delay reason comment (first seen)
2.12	Urgent cancer referral type
2.14	Waiting time adjustment (first seen)
2.15	Waiting time adjustment reason (first seen)
2.16	Source of referral for out-patients
3	**Imaging**
3.2	Clinical intervention date (cancer imaging) [Date of imaging]
3.3	Cancer imaging modality [Imaging Modality]
3.4	Anatomical examination site [Anatomical Site Examined]
4	**Diagnosis**
4.1	Diagnosis date (cancer) [Date of diagnosis]
4.2	Primary diagnosis (ICD) [Primary Site]

ID	Data Item
4.3	Tumour laterality [Laterality]
4.4	Basis of diagnosis (cancer) [Basis of diagnosis]
4.5	Histology (SNOMED) [Histology]
5	**Cancer Care Plan**
5.1	MDT discussion indicator [Was this cancer care plan discussed at an MDT meeting?]
5.2	Multi-disciplinary team date [The date of the MDT meeting at which the cancer care plan was discussed]
5.3	Careplan agreed date [Cancer care plan date]
5.5	Cancer careplan intent [Cancer care plan intent]
5.6	Planned cancer treatment type [Management modality]
5.7	Treatment type sequence (cancer) [Treatment type sequence]
5.9	Co-morbidity index for adults-ACE 27 [Co-morbidity index]
5.10	Performance status (adult) [Performance status]
6	**Staging**
6.1	T category (final pre-treatment) [Final pre-treatment T category]
6.2	Staging certainty factor (T category) [Certainty factor for T category]
6.3	N Category (final pre-treatment) [Final pre-treatment N category]
6.4	Staging certainty factor (N category) [Certainty factor for N category]
6.5	M category (final pre-treatment) [Final pre-treatment M category]

ID	Data Item
6.6	Staging certainty factor (M category) [Certainty factor for M category]
6.7	TNM category (final pre-treatment) [Overall pre-treatment stage group]
6.8	Staging certainty factor (TNM category) [Certainty factor for TNM stage]
6.10	TNM category (integrated) [Overall Pathological TNM stage grouping - integrated stage]
6.11	T category (integrated stage) [Integrated stage - T category]
6.12	N category (integrated stage) [Integrated stage - N category]
6.13	M category (integrated stage) [Integrated stage - M category]
7	**Surgery and Other Procedures**
7.4	Cancer treatment intent [Treatment intent]
7.5	Decision to treat (surgery) [Date of decision to operate]
7.9	Procedure date [Date of surgery]
7.10	Primary procedure (OPCS) [Main surgical procedure]
7.11	Procedure (OPCS) [Sub-procedure]
7.13	Discharge destination (hospital provider spell) [Discharge destination]
8	**Pathology Details**
8.1	Pathology investigation type [Report Type]
8.3	Investigation result date [Date specimen reported]
8.10	Histology (SNOMED) [Histology]

ID	Data Item
8.13	Excision margin [Excision Margins]
8.22	Specimen nature [Nature of specimen]
9	**Chemotherapy and other drugs**
9.4	Decision to treat date (Anti-cancer drug regimen) [Date of decision to treat with drug therapy]
9.7	Drug therapy type [Drug therapy type]
9.8	Drug treatment intent [Treatment intent]
9.10	Start date (anti-cancer drug regimen) [Drug treatment start date]
10	**Radiotherapy (Teletherapy)**
10.3	Decision to treat date (teletherapy treatment course) [Date of decision to treat]
10.6	Cancer treatment intent [Treatment intent]
10.7	Radiotherapy anatomical treatment site [Anatomical treatment site]
10.8	Start course ((teletherapy treatment course) [Teletherapy start date]
11	Radiotherapy (Brachytherapy)
11.3	Decision to treat date (Brachytherapy treatment course) [Date of decision to treat]
11.6	Cancer treatment intent [Treatment intent]
11.9	Start date (Brachytherapy treatment course) [Brachytherapy start date]

ID	Data Item
12	**Palliative Care**
12.1	Decision to treat date (specialist palliative treatment course) [Date of decision to treat]
12.2	Start date (specialist palliative treatment course) [Specialist Palliative Care start date]
13	**Clinical Trials** Note: Clinical Trials information will be completed for every Clinical Trial in which the patient is involved.
13.1	Patient trial status (cancer) [Clinical trial status]
14	**Clinical Status Assessment**
14.1	Clinical status assessment date (cancer) [Date of contact]
14.2	Primary tumour status [Primary tumour status]
14.3	Nodal status [Nodal status]
14.4	Metastatic status [Metastatic status]
14.10	Morbidity code (chemotherapy) [Treatment related morbidity]
14.11	Morbidity code (radiotherapy) [Treatment related morbidity]
14.12	Morbidity code (combination) [Treatment related morbidity]
15	**Death Details**
15.1	Death date [Date of death]

ID	Data Item	Description	Codes and Classifications
HN.11	Symptoms first noted date [Date symptoms first noted]	The month/year the patient first noted any symptoms related to the site of cancer. This can be an approximate date	Date format of mm/yyyy. If the month is not known it is usual to choose the middle of the year e.g. 06/1999
HN.19	Contact date (Dietician initial) Date of first assessment with dietician	The date that the patient was first assessed by a dietician	Date format
HN.20	Date communication sent to primary care following care plan agreed	This is the date of sending of notification of the care plan details to primary care following the care plan being agreed with the patient	Date format
HN.21	Date of image request (cancer imaging)	The date on which imaging is requested that contributes to pre treatment staging	Date format
HN.22	Date of first pre treatment dental assessment	Within the care spell this is the date of the first dental assessment by a dentally qualified practitioner, which contributes to preparation for treatment	Date format
HN.23	Date of first contact with speech and language therapist	Within the care spell this is the date of the first contact language professional which contributes to preparation for treatment	Date format with a qualified speech and

Site specific dataset items

DAHNO Application manuals

The following set of manuals are available on: www.ic.nhs.uk or (www.DAHNO.com) under the National Clinical Audit Support Programme, Head and Neck Audit, 'Guidance for New Users':

- DAHNO Guide to the Data Manual
- Introduction: Volumes 1-5
- Volume 1: Summary Guide
- Volume 2: System Administration
- Volume 3: Explaining Data Collection
- Volume 4: Using DAHNO
- Volume 5: Online Reports and Analysis
- DAHNO Data Manual v1.1
- DAHNO Subset of Cancer Dataset 4.0 v1.0

Appendix 6

DAHNO 'first priority' outputs (larynx and oral cavity)

AGREED BY BAHNO AUDIT AND DATASET GROUP AND THE HEAD AND NECK CLINICAL REFERENCE GROUP

VERSION 1.0 FEBRUARY 2003

1. DEMOGRAPHY, CASEMIX AND SOCIO ECONOMIC STATUS

1.1 Number of patients registered per year with new head and neck primaries of the larynx and oral cavity (divided into the total seen by the specialist team and the local 'denominator' population derived from all available sources).

1.2 Age and sex distributions.

1.3 Distribution of stage at point of treatment decision, and final definitive staging to include pathological TNM (pTNM) (including 'C' certainty factor relating to TNM stage and date of staging).

1.4 Distribution of Performance Status at point of treatment decision.

1.5 Presence or absence of significant comorbidity at index point of diagnosis (ACE-27).

1.6 Distribution of diagnosis, treatment and outcome by socio economic super-group, derived from the postcode.

2. DIAGNOSTIC AND STAGING PROCESS, WAITING TIMES

2.1 Source of referral to specialist team (2ww v non 2ww)(primary v secondary).

2.2 Interval from first symptom to referral to specialist team.

2.3 Time to first appointment from referral.

2.4 Time to diagnosis from referral.

2.5 Time from biopsy to its reporting.

2.6 Time to decision to treat from diagnosis, expressed as:

2.6a Time to MDT ('triage' date) from diagnosis.

2.6b Time to careplan date agreed from diagnosis.

2.6c Time to sending communication to primary care from date careplan agreed.

2.7 % discussed at MDT meeting.

2.8 % with histological confirmation prior to cancer careplan.

2.9 % with staging information recorded at time of cancer careplan.

2.10 % having chest imaging by CXR or CT prior to cancer careplan.

2.11 Time from decision to make imaging request to reporting for imaging (CT / MRI) contributory to pre-treatment staging complying with college guidelines.

2.12 Time to first definitive treatment from diagnosis.

2.13 Time from surgical resection to histological reporting on resective specimen.

2.14 Time from referral to first definitive treatment.

2.15 Time from date of surgery to first treatment for post-operative radiotherapy.

3. TREATMENT: SQUAMOUS CELL CARCINOMA LARYNX – all cancer sites

(Recognising the need to record more than one treatment modality if applicable).

3.1 % having surgical resection with curative intent.

3.2 % by category of clearance for surgical resection margins.

3.3 % having pre-treatment dental assessment.

3.4 % having pre-operative speech and swallowing assessment (includes for laser cordectomy).

3.5 % having pre-operative / pre-treatment (includes radio and chemo therapy) dietetic assessment.

3.6 % receiving each category of surgical procedure (including surgery to neck and surgical voice restoration).

3.7 % having radical radiotherapy (including post-operative planned and unplanned).

3.8 % having palliative treatment by type (i.e. radiotherapy, chemotherapy and surgery).

3.9 % having chemotherapy (including categories such as 'adjuvant' and 'neo adjuvant').

3.10 % referred to specialist palliative care team.

3.11 % receiving no specific treatment (including active monitoring category).

3.12 % patients where careplan agreed matches careplan delivered.

4. TREATMENT: SQUAMOUS CELL CARCINOMA ORAL CAVITY – all cancer sites (Recognising the need to record more than one treatment modality if applicable).

4.1 % having pre-treatment dental assessment.

4.2 % having surgical resection with curative intent.

4.3 % by category of clearance for surgical resection margins.

4.4 % having pre-operative speech and swallowing assessment.

4.5 % having pre-operative / pre-treatment dietetic assessment.

4.6 % receiving each category of surgical procedure (including surgery to neck).

4.6b type of flap repair (if applicable).

4.7 % having radical radiotherapy (including brachytherapy, post-operative planned and unplanned).

4.8 % having palliative treatment by type (i.e. radiotherapy, chemotherapy and surgery).

4.9 % having chemotherapy (including categories such as 'adjuvant' and 'neo adjuvant').

4.10 % referred to specialist palliative care team.

4.11 % receiving no specific treatment (including active monitoring category).

4.12 % patients where careplan agreed matches careplan delivered.

5. PATIENT OUTCOMES

5.1 1 year survival (survival to be expressed in a variety of ways including age-adjusted all-cause mortality and disease-specific mortality – which will require the recording of cause of death and source of this information).

5.2 2 year survival.

5.3 5 year survival.

5.4 Number (%) of treatment-related deaths (to include death within 30 days of surgery and / or within the same admission).

5.5 Locoregional recurrence within 1 year and 2 years of diagnosis (by treatment and tumour type-which will require recording of recurrence by type).

6. CLINICAL TRIALS

6.1 % entered into national clinical trials at cancer careplan.

Appendix 7

UICC 5 TMN Classification of Malignant Tumours

UICC International Union Against Cancer
TNM Classification of Malignant Tumours Fifth Edition 1997– Edited by L.H. Sobin and Ch. Wittekind - John Wiley and Sons Inc. Publication

Larynx (C32.0, 1, 2, C10.1)

Anatomical Sites and Subsites

1 Supraglottis (C32.1)

(i) Suprahyoid epiglottis [including tip, lingual (anterior) (C10.1), and laryngeal surfaces].

(ii) Aryepiglottic fold, laryngeal aspect.

(iii) Arytenoid.

(iv) Infrahyoid epiglottis.

(v) Ventricular bands (false cords).

2 Glottis (C32.0)

(i) Vocal cords.

(ii) Anterior commissure.

(iii) Posterior commissure.

3 Subglottis (C32.2)

TNM Clinical Classification

T- Primary Tumour

TX Primary tumour cannot be assessed.

T0 No evidence of primary tumour.

Tis Carcinoma in situ.

Supraglottis

T1 Tumour limited to one subsite of supraglottis with normal vocal cord mobility.

T2 Tumour invades mucosa of more than one adjacent subsite of supraglottis or glottis or region outside the supraglottis (e.g., mucosa of base of tongue, vallecula, medial wall of piriform sinus) without fixation of the larynx.

T3 Tumour limited to larynx with vocal cord fixation and/or invades any of the following: postcricoid area, pre-epiglottic tissues, deep base of tongue.

T4 Tumour invades through the thyroid cartilage and/or extends into soft tissues of neck, thyroid and/or oesophagus.

Glottis

T1 Tumour limited to vocal cord(s) (may involve anterior or posterior commissure) with normal mobility.

T1a Tumour limited to one vocal cord.

T1b Tumour involves both vocal cords.

T2 Tumour extends to supraglottis and/or subglottis, and/or with impaired vocal cord mobility.

T3 Tumour limited to larynx with vocal cord fixation.

T4 Tumour invades through the thyroid cartilage, and/or extends to other tissues beyond the larynx, e.g., trachea, soft tissues of the neck, thyroid, pharynx.

Subglottis

T1 Tumour limited to subglottis.

T2 Tumour extends to vocal cord(s) with normal or impaired mobility.

T3 Tumour limited to larynx with vocal cord fixation.

T4 Tumour invades through cricoid or thyroid cartilage and/or extends to other tissues beyond the larynx, e.g., trachea, soft tissues of the neck, thyroid, oesophagus.

Oral cavity (C02 – C06)

Anatomical Sites and Subsites

1 Buccal Mucosa.

(i) Mucosa of upper and lower lips (C00.3,4).

(ii) Cheek mucosa (C06.0).

(iii) Retromolar areas (C06.2).

(iv) Bucco-alveolar sulci, upper and lower (vestibule of mouth) (C06.1).

2 Upper alveolus and gingiva (upper gum) (C03.0).

3 Lower alveolus and gingiva (lower gum) (C03.1).

4 Hard palate (C05.0).

5 Tongue.

(i) Dorsal surface and lateral borders anterior to vallate papillae (anterior two-thirds) (C02.0,1).

(ii) Inferior (ventral) surface (C02.2).

6 Floor of mouth (C04).

TNM Clinical Classification

T- Primary Tumour

TX Primary tumour cannot be assessed.

T0 No evidence of primary tumour.

Tis Carcinoma in situ.

T1 Tumour 2cm or less in greatest dimension.

T2 Tumour more than 2cm but not more than 4cm in greatest dimension.

T3 Tumour more than 4cm in greatest dimension.

T4a (oral cavity) Tumour invades adjacent structures e.g. through cortical bone, into deep/extrinsic muscle of tongue, maxillary sinus, or skin.

N- Regional Lymph Nodes

NX Regional lymph nodes cannot be assessed.

N0 No regional lymph node metastasis.

N1 Metastasis in a single ipsilateral lymph node, 3cm or less in greatest dimension.

N2 Metastasis in a single ipsilateral lymph node, more than 3cm but not more than 6cm in greatest dimension; or in multiple ipsilateral lymph nodes, none more than 6cm in greatest dimension; or in bilateral or contralateral lymph nodes, none more than 6cm in greatest dimension.

N2a Metastasis in a single ipsilateral lymph node, more than 3cm but not more than 6cm in greatest dimension.

N2b Metastasis in multiple ipsilateral lymph nodes none more than 6cm in greatest dimension.

N2c Metastasis in bilateral or contralateral lymph nodes, none more than 6cm in greatest dimension.

N3 Metastasis in a lymph node more than 6cm in greatest dimension.

M – Distant Metastasis

MX Distant metastasis cannot be assessed.

M0 No distant metastasis.

M1 Distant metastasis.

Stage Grouping

Stage 0	Tis	N0	M0
Stage I	T1	N0	M0
Stage II	T2	N0	M0
Stage III	T1, T2 T3	N1 N0, N1	M0 M0
Stage IV A	Any T T4	N2 N0, N1	M0 M0
Stage IV B	Any T	N3	M0
Stage IV C	Any T	Any N	M1

Appendix 8

Adult comorbidity Evaluation (ACE-27) UK Values

The following form was developed as an extract from the National Cancer Dataset v4.0. We acknowledge that the intellectual property rights remain with Washington University in St. Louis, Campus Box 8013, 660 So. Euclid Avenue, St Louis MO 63110. It originates from and was developed with the permission of Washington University in St Louis.

Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Cardiovascular System			
Myocardial Infarct	• MI < 6 months	• MI > 6 months ago	• Old MI by ECG only, age undetermined
Angina / Coronary Artery Disease	• Unstable angina	• Chronic exertional angina • Recent (< 6 months) Coronary Artery Bypass Graft (CABG) or Percutaneous Transluminal Coronary Angioplasty (PTCA) • Recent (< 6 months) coronary stent	• ECG or stress test evidence or catheterization evidence of coronary disease without symptoms • Angina pectoris not requiring hospitalization • CABG or PTCA (>6 mos.) • Coronary stent (>6 mos.)
Congestive Heart Failure (CHF)	• Hospitalized for CHF within past 6 months • Ejection fraction < 20%	• Hospitalized for CHF >6 months prior • CHF with dyspnea which limits activities	• CHF with dyspnea which has responded to treatment • Exertional dyspnea • Paroxysmal Nocturnal Dyspnea (PND)
Arrhythmias	• Ventricular arrhythmia < 6 months	• Ventricular arrhythmia >6 months • Chronic atrial fibrillation or flutter • Pacemaker	• Sick Sinus Syndrome
Hypertension	• DBP>130 mm Hg • Severe malignant papilledema or other eye changes • Encephalopathy	• DBP 115-129 mm Hg • DBP 90-114 mm Hg while taking antihypertensive medications • Secondary cardiovascular symptoms: vertigo, epistaxis, headaches	• DBP 90-114 mm Hg while not taking antihypertensive medications • DBP <90 mm Hg while taking antihypertensive medications • Hypertension, not otherwise specified
Venous Disease	• Recent PE (< 6 mos.) • Use of venous filter for PE's	• DVT controlled with Coumadin or heparin • Old PE > 6 months	• Old DVT no longer treated with Coumadin or Heparin
Peripheral Arterial Disease	• Bypass or amputation for gangrene or arterial insufficiency < 6 months ago • Untreated thoracic or abdominal aneurysm (>6 cm)	• Bypass or amputation for gangrene or arterial insufficiency > 6 months ago • Chronic insufficiency	• Intermittent claudication • Untreated thoracic or abdominal aneurysm (< 6 cm) • s/p abdominal or thoracic aortic aneurysm repair

Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Respiratory System			
	• Marked pulmonary insufficiency • Restrictive Lung Disease or COPD with dyspnea at rest despite treatment • Chronic supplemental O2 • CO2 retention (pCO2 > 6.7 kPa) • Baseline pO2 < 6.7 kPa • FEV1 (< 50%)	• Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which limits activities • FEV1 (51%-65%)	• Restrictive Lung Disease or COPD (chronic bronchitis, emphysema, or asthma) with dyspnea which has responded to treatment • FEV1 (66%-80%)
Gastrointestinal System			
Hepatic	• Portal hypertension and/or esophageal bleeding < 6 mos. (Encephalopathy, Ascites, Jaundice with Total Bilirubin > 34mmol/l)	• Chronic hepatitis, cirrhosis, portal hypertension with moderate symptoms "compensated hepatic failure"	• Chronic hepatitis or cirrhosis without portal hypertension • Acute hepatitis without cirrhosis • Chronic liver disease manifested on biopsy or persistently elevated bilirubin (>51mmol/l)
Stomach / Intestine	• Recent ulcers < 6 months requiring > 6 units of blood transfusion • Acute or chronic pancreatitis with major complications (phlegmon, abscess, or pseudocyst)	• Ulcers requiring surgery or transfusion of < 6 units of blood	• Diagnosis of ulcers treated with meds • Chronic malabsorption syndrome • Inflammatory bowel disease (IBD) on meds or h/o with complications and/or surgery
Pancreas	• Acute or chronic pancreatitis with major complications (phlegmon, abscess, or pseudocyst)	• Uncomplicated acute pancreatitis • Chronic pancreatitis with minor complications (malabsorption, impaired glucose tolerance, or GI bleeding)	• Chronic pancreatitis w/o complications
Renal System			
End-stage renal disease	• Creatinine > 265 umol/l with multi-organ failure, shock, or sepsis • Acute dialysis	• Chronic Renal Insufficiency with creatinine > 265 umol/l • Chronic dialysis	• Chronic Renal Insufficiency with creatinine 177-265umol/l.

Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Endocrine System (Code the comorbid ailments with the (*) in both the Endocrine system and other organ systems if applicable)			
Diabetes Mellitus	• Hospitalization < 6 months for DKA • Diabetes causing end-organ failure • retinopathy • neuropathy • nephropathy* •coronary disease* • peripheral arterial disease*	• IDDM without complications • Poorly controlled AODM	• AODM controlled by oral agents only
Neurological System			
Stroke	• Acute stroke with significant neurologic deficit	• Old stroke with neurologic residual	• Stroke with no residual • Past or recent TIA
Dementia	• Severe dementia requiring full support for activities of daily living	• Moderate dementia (not completely self-sufficient, needs supervising)	• Mild dementia (can take care of self)
Paralysis	• Paraplegia or hemiplegia requiring full support for activities of daily living	• Paraplegia or hemiplegia requiring wheelchair, able to do some self care	• Paraplegia or hemiplegia, ambulatory and providing most of self care
Neuromuscular	• MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder and requiring full support for activities of daily living	• MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder, but able to do some self care	• MS, Parkinson's, Myasthenia Gravis, or other chronic neuromuscular disorder, but ambulatory and providing most of self care
Psychiatric			
	• Recent suicidal attempt • Active schizophrenia	• Major depression or bipolar disorder uncontrolled • Schizophrenia controlled w/ meds	• Major depression or bipolar disorder controlled w/ medication
Rheumatologic (Incl. Rheumatoid Arthritis, Systemic Lupus, Mixed Connective Tissue Disorder, Polymyositis, Rheumatic Polymyositis)			
	• Connective Tissue Disorder with secondary end-organ failure (renal, cardiac, CNS)	• Connective Tissue Disorder on steroids or immunosuppressant medications	• Connective Tissue Disorder on NSAIDS or no treatment
Immunological System (AIDS should not be considered a comorbidity for Kaposi's Sarcoma or Non-Hodgkin's Lymphoma)			
AIDS	• Fulminant AIDS w/KS, MAI, PCP (AIDS defining illness)	• HIV+ with h/o defining illness. CD4+ < 200/mL	• Asymptomatic HIV+ patient. • HIV+ w/o h/o AIDS defining illness. CD4+ > 200mL

Cogent comorbid ailment	Grade 3 Severe Decompensation	Grade 2 Moderate Decompensation	Grade 1 Mild Decompensation
Malignancy (Excluding Cutaneous Basal Cell Ca., Cutaneous SCCA, Carcinoma in-situ, and Intraepithelial Neoplasm)			
Solid Tumor including melanoma	• Uncontrolled cancer • Newly diagnosed but not yet treated • Metastatic solid tumor	• Any controlled solid tumor without documented metastases, but initially diagnosed and treated within the last 5 years	• Any controlled solid tumor without documented metastases, but initially diagnosed and treated > 5 years ago
Leukemia and Myeloma	• Relapse • Disease out of control	• 1st remission or new dx <1yr • Chronic suppressive therapy	• H/o leukemia or myeloma with last Rx > 1 yr prior
Lymphoma	• Relapse	• 1st remission or new dx <1yr • Chronic suppressive therapy	• H/o lymphoma w/ last Rx >1 yr prior
Substance Abuse (Must be accompanied by social, behavioral, or medical complications)			
Alcohol Illicit Drugs	• Delirium tremens • Acute Withdrawal Syndrome	• Active alcohol abuse with social, behavioral, or medical complications • Active substance abuse with social, behavioral, or medical complications	• H/o alcohol abuse but not presently drinking • H/o substance abuse but not presently using
Body Weight			
Obesity		• Morbid (i.e., BMI>38)	

OVERALL COMORBIDITY SCORE (Circle one.)	0 None	1 Mild	2 Moderate	3 Severe	9 Unknown

Appendix 9

Definition of cancer waiting times in England and in Wales

The Cancer Waiting Time targets in England

The National Cancer Plan for England was published in September 2000. Within the Plan there are a number of commitments and targets relating to waiting times for treatment. A document **"CANCER WAITING TARGETS – A GUIDE (VERSION 5)"** can be found at:
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_063067
It provides answers to frequently asked questions about the 2001, 2002 and 2005 Cancer Plan targets for England which are:

- **Maximum two month wait from urgent GP referral for suspected cancer to first definitive treatment for all cancers by 2005 ("62 day target").** This target only relates to patients referred under the TWO WEEK WAIT RULE. The date of first definitive treatment is the date of admission for a surgical procedure or actual date of first treatment for other therapies (eg for radiotherapy or chemotherapy).
- **Maximum one month wait from diagnosis (DECISION TO TREAT DATE) to first definitive treatment for all cancers by 2005 ("31 day target").** This target relates to ALL cancer patients including those referred under the TWO WEEK WAIT RULE. The decision to treat date, is the date that the consultant and the patient discuss the treatment options and decide together on a definitive treatment plan.

In addition there is also the existing two week waiting time standard:

- **Maximum two week wait for an urgent GP referral for suspected cancer to date first seen for all suspected cancers,** as defined in Health Service Circular (HSC) 1999/205 (www.dh.gov.uk). The two week wait period is defined as the elapsed time between the GP making an urgent referral for suspected cancer and the date the patient is first seen in outpatients. All the data items used to calculate this period are contained within DSCN 22/2002. For clinicians this is further defined in the referral guidelines for suspected cancer which are published by NICE (though this is primarily guidance for general practitioners).

The Cancer Waiting Time targets in Wales

The Cancer Targets feature in WHC (2005) 027 ' Monthly data collection of cancer waiting times to start of definitive treatment' and are for full compliance as part of Service and Financial Framework 2006/07.

The cancer waiting times target for Wales are as follows:

a) **Newly diagnosed cancer patients that have been referred as Urgent Suspected Cancer (USC) and confirmed as urgent by the specialist, to start definitive treatment within 2 months (62 days) from receipt of referral at the hospital.**

b) **Newly diagnosed cancer patients not included as USC referrals to start definitive treatment within 1 month (31 days) of a decision to treat.**

In Wales, the specialist can up and down grade the initial referral from primary care depending on the information provided. The National Cancer Standards require GPs to be informed of all down graded referrals.

The targets should be complied with in full by December 31st 2006.

Defining the statements within the targets.

Newly diagnosed cancer patients that have been referred as urgent suspected cancer(USC) and confirmed as urgent by the specialist to start definitive treatment within 2 months (62 days) from receipt of referral at the hospital.

- referred as a USC - a suspicion of cancer is stated by the GP and confirmed by the specialist
- referred as a USC - not restricted to designated USC only referral methods e.g. fax lines
- referred as a USC – will include non USC GP referrals upgraded to USC by the specialist when he/she has viewed the referral information
- receipt of referral by the hospital – if confirmed as USC by the specialist the 62 days commences from when the hospital received the referral not when the specialist saw the referral.

- first definitive treatment – any initial treatment that treats the patients cancer, stabilizes their symptoms from cancer, stabilizes their health so cancer treatment can commence.

Newly diagnosed cancer patients not included as USC referrals to start definitive treatment within 1 month (31 days) of a decision to treat.

- not included as USC referrals – any patient who was not referred by their GP as a USC or not referred by their GP and upgraded by the specialist on analysis of the GP referral
- decision to treat – the point in time when a clear range of treatment options is offered to the patient by an MDT member and the patient elects for a given option.

The last stage above also has an application within the pathway of the 62 day target.

Appendix 10

Scenarios in data collection

10.1 Key findings from development of a data collection process at the Freeman Hospital Newcastle–upon–Tyne (with thanks to Vin Paleri)

- Designate a lead clinician responsible for setting up the data collection.
- Key personnel (clinicians and non-clinicians) involved in data collection should attend DAHNO workshops prior to commencing data collection.
- Identify the local nodes where the DAHNO software will be installed.
- Ensure all groundwork is done prior to starting data collection. This involves identifying personnel involved in data collection, mapping out the local patient pathway so that the time and place of data collection can be agreed upon, and managerial support.
- Introduce the system to the multi-disciplinary team and other stakeholders in the hospital to encourage local ownership.
- A clear understanding of the hierarchy in the DAHNO software is essential. A printout of this near the workplace is very helpful in the early days.
- Set a target date for data collection and ensure all relevant personnel are aware of this.
- The hospital IT department must be appraised of the software requirements and encouraged to sort out firewall and platform issues well ahead of the planned start date.
- Inputting a dummy patient helps understand the layers of data required.
- If real time input of data is not planned, a data extraction form for non-clinical data such as referral dates and demographics will make the process easier.

10.2 Proforma for collation of speech and language therapy at Doncaster Royal Infirmary (with thanks to Mark Watson)

- The proforma is completed at regular intervals via the speech and language therapist and passed to the MDT co-ordinator who then enters into DAHNO avoiding multiple requests and notes access.

Doncaster and Bassetlaw Hospitals NHS Foundation Trust

National Clinical Head and Neck Audit- DAHNO Project (**D**ata for **H**ead and **N**eck **O**ncology)

Proforma for collection of data from the Speech and Language Therapy Department for Larynx and Oral Cavity Head and Neck Patients

SPEECH AND LANGUAGE THERAPIST – Record the date of the patient's **first assessment** with a qualified speech and language professional which contributes to preparation for treatment.

Patients Name, D.O.B, Address and Hospital Number (Pts Label)	**Date of the Assessment**

Please return completed form to: Joyce Harris, Cancer Data Manager, Cancer Services, c/o Clinical Audit, Bassetlaw Hospital, Worksop.

Glossary

2WW	Two Week Wait
Adjuvant	a treatment given in concert with another to boost its activity
Aetiology	part of medical science dealing with the causes of disease
Alveolus	the portion of the jaw containing the teeth
Aspiration	withdrawal of fluids or gases from a cavity
BAHNO	British Association of Head and Neck Oncologists
Barium	a metallic element (in barium sulphate form) used in diagnostic imaging due to its propensity to absorb X-rays
Biopsy	removal and examination of tissue for diagnostic purposes
Brachytherapy	treatment modality using implantation of radioactive material
Buccal mucosa	mucous membrane of the mouth or inside of cheek
Cancer centre	specialised unit within a single or multiple hospitals that refers, diagnoses and treats cancer patients
Cancer site	area where cancer is located
CaNISC	Cancer Network Information System Cymru.
Careplan	represents the point in the patient pathway where a plan of treatment is proposed and thus an appropriate point to assess and record a patient's fitness
Casemix	a means of classifying hospital patients to provide a common basis for comparing cost effectiveness and quality of care across hospitals.
CCAD	Central Cardiac Audit Database
CDS	Community Dental Service
CEU	Clinical Effectiveness Unit
CHART	continuous hyper fractionated accelerated radiotherapy
Chemoradiation	a combination of chemotherapy and radiotherapy
Chemotherapy	drugs used in the treatment of cancer
Child document	sub-document of a parent (top level) document
Co-morbidity	co existent illness(es) to the disease under consideration
Cordectomy	removal of the vocal chords
CSV	Comma Separated value
CT scan	computerised tomography scan - a radiological investigation
Curative	intending to cure

CXR	chest X-ray
Cytologist	medically qualified specialist in the study of cells and disease
Cytology	study of cells and disease
DAHNO	**D**ata for **H**ead and **N**eck **O**ncology
DAHNO application	software used to collate national, comparative head and neck cancer data
Dataset	collection of data items
Decompensation	the functional deterioration of a previously working structure or system. Decompensation may occur due to fatigue, stress, illness, or old age. When a system is "compensated", it is able to function despite stressors or defects. Decompensation describes an inability to compensate for these deficiencies
Demographic	a statistic characterizing human populations (or segments of human populations) broken down by age or sex or income etc.
Deprivation	absence of expected level of social provision
DH	Department of Health
Diagnosis	confirming the presence of a disease
Dietician	Allied Health Professional specialising in aspects of nutrition
Dorsal	top surface
DSCN	Data Set Change Notification
Early adopter	team or individual taking up a new idea ahead of majority
Endolaryngeal	describing treatment of the larynx via a hollow endoscope
Endoscopy	visualisation of hollow organs
ENT	Ear, Nose and Throat
Epidemiologist	specialist in the study of prevalence of disease
Excision	removal of an area of tissue
Extensive resection	extension of surgical procedure to remove greater volume of tissue than normally required for named procedure
Flap repair	reconstructive surgery utilising a flap of tissue
GDP	General Dental Practitioner
Gingiva	mucosal tissue between and around teeth
Glossectomy	removal of the tongue
Glottis	the vocal apparatus of the larynx; the true vocal folds and the space between them where the voice tone is generated

GMP	General Medical Practitioner
GP	General Practitioner
Healthcare Commission	an independent body, to promote and drive improvement in the quality of healthcare and public health in England and Wales.
Hemimandibulectomy	removal of half the mandible
Histology	microscopic study of cells and tissues
Histopathologist	medically qualified specialist in histology and pathology
HNCRG	Head and Neck Clinical Reference Group
Homogeneous	of similar consistency
Hypopharynx	the lowest section of the pharynx
IBM Lotus Domino®	the server architecture upon which the central DAHNO application database replica resides
IBM Lotus Notes®	the client software that renders the functionality of the DAHNO database to its users
IC	The Information Centre for health and social care (NHS body)
ICD-10	International Classification of Diseases version 10 (a coding nomenclature prepared by the World Health Organisation).
IMD	Index of Multiple Deprivation
IOG	Improving Outcomes Guidance - issued by NICE
ISB	Information Standards Board
Laryngeal	of the larynx
Laryngectomy	removal of larynx (voice box)
Larynx	voice box - anatomic cartilage and soft tissue structure
LDP	local delivery plans
Lesion	abnormal area of tissue
Linear accelerator	radiotherapy machine to deliver high energy beam to treat cancer
Locoregional	area surrounding tumour and its expected lymph node drainage
Lymph node	a bean shaped focus of lymphoid tissue present in many areas of the body forming part of the immune system
Malignant	cancerous
Mandibulectomy	removal of mandible
Mandibulotomy	division of mandible - usually for surgical access

Maxillectomy	removal of maxilla
Maxillofacial	of the face and jaws
MDT	Multi Disciplinary Team – a team of clinical specialists assembled to discuss and agree the appropriate care for a patient
Meta analysis	statistical technique to summate separate statistical analyses
Metastasis	distant spread of tumour
MRI scan	Magnetic Resonance Imaging – a scanning technique using magnetic and radio-waves
Mucosa	mucous membrane
Multimodality	combination of treatments
NCASP	National Clinical Audit Support Programme
NCDS	National Cancer Dataset – the standardised set of data items used in the collection of cancer data
Neo-adjuvant	a substance given ahead of another treatment to boost its effect
Neoplasm	new growth of tissue in part of body
NHSIA	NHS Information Authority – the name of the NHS body now known as 'The Information Centre'
NICE	National Institute for Clinical Excellence - an independent organisation responsible for providing national guidance on promoting good health and preventing and treating ill health
NOS	Not Otherwise Specified
NSF	National Service Framework – Dept. of Health long term strategies for improving specific areas of care. They set measurable goals within set time frames
Oncologists	medically qualified non surgical specialists in cancer management
ONS	Office for National Statistics
Oral cavity	the mouth: anatomic area bounded by the lips palate and pharynx
Oropharyngeal	anatomical subsite the oropharynx e.g. a tumour arising in the oropharynx
Osteoradionecrosis	breakdown of bone as a consequence of previous radiotherapy
Palate	'roof of the mouth' comprising bony anterior portion and soft tissue portion posteriorly
Palliative care	care to alleviate a disease without intent of cure
Parent document	top level document that has subdocuments beneath it

PAS	Patient Administration System
Pathology	study of organs of the body in disease
Pathway	describes stages in the journey of care for a disease
PCT	Primary Care Trust
PET scan	Positron Emission Tomography - a nuclear medicine technique which produces a three-dimensional image or map of functional processes in the body.
Pharynx	anatomical area from back of nose to start of oesophagus (gullet)
PIAG	Patient Information Advisory Group - PIAG was established to provide advice on issues of national significance involving the use of patient information and to oversee arrangements created under Section 60 of the Health and Social Care Act 2001. Its membership is drawn from patient groups, healthcare professionals and regulatory bodies.
Prognosis	predicted outcome of a disease
Radiologist	medically qualified imaging specialist
Radiotherapy (RT)	cancer treatment using high energy beams
RCT	Randomised Control Trial - the essential characteristics of a RCT are that there will be a comparison between a treatment and placebo group. Great care is taken to avoid bias when collecting the data and assigning subjects (randomly) to their respective groups.
Resective pathology	pathology of a surgically removed specimen
Retromolar area	the area directly behind the molar teeth
SALT	Speech and Language Therapists
Squamous cell carcinoma (SCC)	the commonest cancer of mucous membranes in the head and neck
Stage certainty	validation of diagnostic method used to derive stage of cancer
Subglottis	area of voice box below vocal cords
Supraglottis	upper portion of voice box above vocal cords
SUS	Secondary Uses Services
Surgeon	medically qualified specialist who performs diagnostic assessments and operative procedures
SWAHN	South West Audit of Head and Neck Cancer
Teletherapy	high energy external beam used in the treatment of cancer
Thorax	chest cavity

TNM	Tumour, Node, Metastasis. Clinical Classification of anatomical extent of cancer
Tomography	multiple slice x-ray
Triage	preliminary assessment to determine future pathway of care
Tuberculosis	infectious granulomatous disease
Tumour	swelling or abnormal growth
Voice Restoration	means of achieving voice in a patient who has had a laryngectomy
UICC	International Union Against Cancer (French Acronym - Union Internationale Contre le Cancer)
Ulceration	erosion of a mucosal lining
Ultrasonography	technique of high frequency sound scans to visualise body structures
Upper aero-digestive tract	anatomic area from nose and mouth to start of gullet, includes both respiratory passages (nose and voice box) as well as mouth and pharynx

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